

# Open Research Online

---

The Open University's repository of research publications and other research outputs

## An investigation into fatigue following traumatic brain injury

### Thesis

#### How to cite:

Pedroza, Catharine (1999). An investigation into fatigue following traumatic brain injury. PhD thesis The Open University.

For guidance on citations see [FAQs](#).

© 1999 The Author



<https://creativecommons.org/licenses/by-nc-nd/4.0/>

Version: Version of Record

Link(s) to article on publisher's website:

<http://dx.doi.org/doi:10.21954/ou.ro.0000e288>

---

Copyright and Moral Rights for the articles on this site are retained by the individual authors and/or other copyright owners. For more information on Open Research Online's data [policy](#) on reuse of materials please consult the policies page.

---

[oro.open.ac.uk](http://oro.open.ac.uk)

CATHARINE PEDROZA BSc (Hons)

**AN INVESTIGATION INTO FATIGUE FOLLOWING  
TRAUMATIC BRAIN INJURY**

A thesis submitted in partial fulfilment of the requirements of the Open  
University for the degree of Doctor of Clinical Psychology

JULY 1999

SALOMONS  
CANTERBURY CHRIST CHURCH UNIVERSITY COLLEGE

19980 words, approx.

# DECLARATION FOR DISSERTATION

## DECLARATION

This work has not previously been accepted in substance for any degree and is not being concurrently submitted in candidature for any degree.

Signed .....  ..... (candidate)

Date ..... 15. 7. 99 .....

## STATEMENT 1

This thesis is the result of my own investigations, except where otherwise stated. Other sources are acknowledged by footnotes giving explicit references. A bibliography is appended.

Signed .....  ..... (candidate)

Date ..... 15. 7. 99 .....

Signed .....  ..... (supervisor)

Date ..... 12. 7. 99 .....

## STATEMENT 2

I hereby give consent for my thesis, if accepted, to be available for photocopying and for inter-library loan, and for the title and abstract to be made available to outside organisations.

Signed .....  ..... (candidate)

Date ..... 15. 7. 99 .....

## **ACKNOWLEDGEMENTS**

Sincere thanks to all those who gave up their time to participate in this study, and who kindly allowed me to interview them in their own homes.

Also many thanks to Mike Oddy for his dedicated supervision and calming influence, to Sue Holttum for always being available on the other end of the telephone to answer queries, and to Margie Callanan for reading a draft of the study. I would also like to thank Wendy Julian for her help and efficiency with administrative tasks.

Finally, thanks to Dawn for reminding me to work when I was getting too relaxed, and to Caroline for reminding me to relax when I was getting too stressed.

To preserve confidentiality, all names in this study have been changed.



*Library authorisation form*  
*DClinPsychol*

Please return this form to the Assistant Director (Registration and Conferences). Open University Validation Services, 344-354 Gray's Inn Road, London WC1X 8BP.

Student: CATHARINE PEDROZA

Validated institution: Salisbury, Canterbury Christ Church University College

Degree for which the thesis is submitted: Doctor of Clinical Psychology

Thesis title: AN INVESTIGATION INTO ~~THE~~ FATIGUE  
FOLLOWING TRAUMATIC BRAIN INJURY

**Part 1 Open University Library Authorisation**

I confirm that I am willing for my thesis to be made available to readers by the Open University Library and for it to be photocopied, subject to the discretion of the Librarian.

Signed C Pedroza Date: October 6 1999

**Part 2 British Library Authorisation**

If you want a copy of your thesis to be available on loan to the British Library Thesis Service as and when it is requested, you must sign a British Library Doctoral Thesis Agreement Form and return it to the Research Degrees Office of the University together with this form. The British Library will publicize the details of your thesis and may request a copy on loan from the University Library. Information on the presentation of the thesis is given in the Agreement form.

The University has decided that your participation in the British Library Thesis Service should be voluntary. Please tick one of the boxes below to indicate your intentions.



I am willing for the Open University to loan the British Library a copy of my thesis: a signed British Library Doctoral Thesis Agreement Form is attached.

or



I do not wish the Open University to loan a copy of my thesis to the British Library.

Signed

C Pedroza

Date: October 6 1999

## ABSTRACT

**Design** This is a cross-sectional study involving quantitative measures and qualitative interviews.

**Participants** Sixteen brain injured men and four brain injured women participated. Eighteen of these had a close relative who also took part.

**Measures** In addition to being interviewed, brain injured participants completed questionnaires on mood, symptoms and fatigue, and a speed of information processing task. Relatives of brain injured people were interviewed and completed the symptom checklist. Correlational analysis was applied to the quantitative measures and qualitative analysis was informed by the grounded theory approach.

**Results** Quantitative measures suggest significant association of subjective perception of fatigue severity with mood and brain injury related symptoms. Relatives' objective perceptions of brain injured relatives' symptoms correlated significantly with subjective views. Subjective perception of fatigue did not correlate significantly with severity of brain injury or information processing speed. Qualitative analysis identified fatigue as a major problem for some people. Descriptions noting the impact of fatigue following injury included increased slowness, decreased energy, and lack of control. Fatigue was commonly considered to be more mental than physical, and was often linked with short temper.

**Conclusions** Findings suggest that fatigue was related less to severity of injury than to psychological and emotional factors. The multidimensional nature of fatigue was confirmed. Links were made with low mood, anxiety, lack of motivation, boredom, and having to cope with 'normal life' following brain injury. The possibility that 'fatigue' is an umbrella term used by some to describe a range of symptoms following brain injury was considered.



# CONTENTS

Acknowledgements

Abstract

Page

<b>1.0 INTRODUCTION</b>	<b>1</b>
<b>1.1 Fatigue and tiredness</b>	<b>1</b>
1.1.1 A note on terminology	1
1.1.2 What is fatigue?	1
1.1.3 Dimensions of fatigue	2
1.1.4 Fatigue and brain injury	3
<b>1.2 Occupational psychology literature</b>	<b>5</b>
1.2.1 Fatigue and performance	5
1.2.2 Shiftwork	5
1.2.3 Nature of work	6
1.2.4 Adrenaline/motivation	7
<b>1.3 The brain</b>	<b>8</b>
1.3.1 Arousal	8
1.3.2 Sleep loss	9
1.3.3 'Worn out' syndrome	9
1.3.4 Information processing	10
<b>1.4 Fatigue and mood</b>	<b>13</b>
<b>1.5 Chronic fatigue syndrome</b>	<b>15</b>
<b>1.6 Summary</b>	<b>17</b>
<b>1.7 Aims of the study</b>	<b>18</b>
<b>1.8 Research questions</b>	<b>19</b>
<b>1.9 Hypotheses</b>	<b>19</b>
 <b>2.0 METHOD</b>	 <b>20</b>
<b>2.1 Design</b>	<b>20</b>
<b>2.2 Participants</b>	<b>21</b>
2.2.1 Exclusion and inclusion criteria	21
2.2.2 Recruitment	21
2.2.3 Contacting prospective participants	21
2.2.4 Response rate	22
<b>2.3 Ethical considerations</b>	<b>22</b>
<b>2.4 Demographic information</b>	<b>23</b>
2.4.1 Gender	23
2.4.2 Nature of accident	23
2.4.3 Length of post traumatic amnesia	23
2.4.4 Work	24
2.4.5 Relatives/close friends	24
<b>2.5 Qualitative questions</b>	<b>24</b>
2.5.1 Evaluation of qualitative findings	25
2.5.1.1 Respondent validity	25

2.5.1.2 Inter-rater reliability	25
2.5.1.3 Auditability	26
<b>2.6 Quantitative measures</b>	<b>26</b>
2.6.1 Background information	26
2.6.2 Speed of information processing task	26
2.6.3 Visual analogue scales	27
2.6.4 Fatigue Assessment Instrument	27
2.6.5 Wimbledon Self Report Scale	29
2.6.6 Brain injury related symptom checklist	29
<b>2.7 Pilot study</b>	<b>30</b>
<b>2.8 Procedure</b>	<b>30</b>
<b>2.9 Analysis</b>	<b>31</b>
2.9.1 Qualitative analysis	31
2.9.2 Quantitative analysis	32
 <b>3.0 RESULTS</b>	 <b>33</b>
 <b>3.1 Measurement of fatigue</b>	 <b>33</b>
3.1.1 Fatigue assessment instrument	33
3.1.2 Visual analogue scales	34
3.1.3 FAI and visual analogue scales	34
3.1.4 Reports of fatigue in the interviews	34
<b>3.2 Quantitative analysis of the data</b>	<b>35</b>
3.2.1 Null hypothesis one	36
3.2.2 Null hypothesis two	36
3.2.3 Null hypothesis three	37
3.2.4 Null hypothesis four	37
<b>3.3 Qualitative analysis of research questions</b>	<b>37</b>
3.3.1 How would you describe tiredness/fatigue?	37
3.3.2 How do you feel/know when you are tired/fatigued?	39
3.3.3 Are you on any medication?	41
3.3.4 How well do you sleep?	42
3.3.5 Are there specific times when you feel tired/fatigued?	43
3.3.6 Are there particular situations when you feel tired/fatigued?	45
3.3.7 What do you think the causes of your tiredness/fatigue are?	46
3.3.8 Change in amount of tiredness/fatigue	47
<b>3.4 Qualitative analysis of additional interview material</b>	<b>49</b>
3.4.1 Energy levels	49
3.4.2 Motivation and strategies	50
3.4.3 Trying too hard	51
3.4.4 Vicious circle of fatigue and activity	52
3.4.5 Lack of motivation/low mood/avoidance	52
3.4.6 Change in quality of fatigue	53
3.4.7 Inter-linked problems	54
<b>3.5 Qualitative analysis of debriefing question</b>	<b>55</b>
<b>3.6 Summary of qualitative analysis of relatives' views</b>	<b>56</b>
3.6.1 Lack of awareness of fatigue	56
3.6.2 Daytime sleep	56
3.6.3 Signs of fatigue	57



3.6.4 Sudden fatigue	57
3.6.5 Reasons for fatigue	58
3.6.6 Hypotheses about fatigue	59
<b>4.0 DISCUSSION</b>	<b>60</b>
4.1 Discussion of research findings	60
4.1.1 Brain injury and fatigue	60
4.1.2 Sleep and fatigue	63
4.1.3 Working, not working and fatigue	64
4.1.4 Mood and fatigue	66
4.1.5 Awareness of fatigue	68
4.1.6 Reduced energy	68
4.2 Methodological considerations	70
4.2.1 Mixed methodology	70
4.2.2 Recruitment	70
4.2.3 Interviews	71
4.2.4 Omissions	72
4.2.5 Final comments on methodology	73
4.3 Clinical implications	74
4.3.1 Education	74
4.3.2 Practical help	74
4.3.3 Emotional support	75
4.4 Future research	75
4.5 Conclusion	76
<b>5.0 REFERENCES</b>	<b>78</b>
<b>Appendices</b>	

## LIST OF TABLES

Table		Page
Table 1	Correlations (Spearman's rho) between factors on the FAI	33
Table 2	Comparison of measures of fatigue using Mann-Whitney tests	35
Table 3	Properties of fatigue described by people with brain injury	38
Table 4	Awareness of fatigue by people with brain injury	39
Table 5	Number of people on medication	41
Table 6	Number of hours slept during the night by participants with brain injury	42
Table 7	Times of day when people with brain injury were most likely to feel fatigued	43
Table 8	Situations commonly associated with fatigue by people with brain injury	45
Table 9	Perceived change in fatigue following injury	47
Table 10	Expectations regarding change in fatigue in people with brain injury	48
Table 11	Change in energy levels following brain injury	49
Table 12	Strategies of people with brain injury to help combat fatigue	51
Table 13	Changes in experience of fatigue following brain injury	53
Table 14	Feelings about having taken part in the study	55
Table 15	Possible reasons for fatigue in addition to brain injury	58

## **PART ONE: INTRODUCTION**

## 1.0 INTRODUCTION

### 1.1 FATIGUE AND TIREDNESS

*Fatigue: Extreme tiredness after exertion; weakness in materials, especially metals, caused by repeated variations of stress; a reduction in the efficiency of a muscle, organ etc., after prolonged activity; an activity that causes fatigue; a non-military duty in the army; tire, exhaust.*

*Tired: Weary, exhausted, ready for sleep.*

The Concise Oxford Dictionary (1991).

#### 1.1.1 A note on terminology

This study focuses on individual experience and understanding of the term 'fatigue'. Because 'tiredness' forms part of the dictionary definition of fatigue, it was used throughout the study in tandem with 'fatigue' to facilitate a breadth of responses from participants.

#### 1.1.2 What is fatigue?

The term fatigue has many uses in the English language. Ream & Richardson's (1996) overview of dictionary definitions of fatigue noted that they share four similar characteristics: fatigue follows exertion, fatigue is associated with physical or mental weariness and exhaustion; fatigue comprises comfortless, troublesome or odious feelings; fatigue causes decreased functional ability, which is often temporary. Brown (1994) notes that fatigue tends to be noted for its consequences rather than its causes.

In 1921 Muscio suggested that the term fatigue 'be absolutely banished from scientific discussion' (p45) because it was so broad. Ream & Richardson (1996) state

that confusion surrounding the term continues. Wessely, Hotopf & Sharpe (1998) describe it as a 'convenient and problematic concept', the essential meaning of which 'can seem vague, elusive and difficult to operationalise' (p1). They suggest that difficulties with the definition of fatigue arise from a failure to differentiate between its various meanings.

Grandjean (1979) explains that at any time an individual 'is in one particular functional state, somewhere between the extremes of sleep and a state of alarm' (p177). Within this range a number of stages exist: deep sleep, light sleep, drowsy, weary, hardly awake, relaxed resting, fresh alert, very alert, stimulated, state of alarm. Grandjean describes mental fatigue as a functional state which prevents us from overstraining ourselves and grades in one direction into sleep and in the opposite direction into a relaxed, restful condition.

### **1.1.3 Dimensions of fatigue**

Wessely *et al.* (1998, after Mosso, 1904) deconstruct the concept of fatigue into 'behaviour', 'feeling state', 'mechanism' and 'context'.

As a behaviour, fatigue may be evident both as affecting the performance of physical work and mental work. As a feeling state, fatigue may be experienced in three main ways. Firstly, as a sensory quality, it might be expressed as weariness or aversion to further effort. Secondly, affective or emotional aspects of fatigue may be linked with irritability, depression, pain, frustration or anxiety. Thirdly, cognitive and evaluative aspects of fatigue might be expressed by self statements concerning bodily feelings, or catastrophic thinking, (e.g., 'I will run out of energy'). As a mechanism, fatigue



may be seen as an internal state (like hunger) and resulting in a tendency towards certain behaviour. Psychological mechanisms of fatigue are considered to be evident in a decrease in performance on mental tasks. Cognitive behavioural theories consider beliefs and expectation, the focus of attention on bodily sensations, and mood and motivation in relation to fatigue. Additionally, the mechanism of fatigue has been considered in terms of a defence against exhaustion (Grandjean, 1979). Finally, fatigue can be considered in context, which gives consideration to temporal, physical and social factors, and demands on the individual.

#### **1.1.4 Fatigue and brain injury**

Fatigue is widely recognised as a common consequence of brain injury (van Zomeren & van den Burg, 1985; Hinkelday & Corrigan, 1990; Ponsford, 1995; Olver, Ponsford & Curran, 1996). Follow-up studies often report that fatigue is noted by research participants as a cause of continued distress. This was found by Hillier, Sharpe & Metzger (1997), in a follow up study of 67 brain injury patients in Australia. Reaction time studies involving brain injured people also report a fatigue effect, causing the individual's reaction times to slow more quickly than control groups, in tasks requiring divided and focused attention (Stuss, Stethem, Hugenholtz, Picton, Pivik & Richard, 1989; van Zomeren & Brouwer, 1987).

Despite these findings, fatigue remains 'poorly understood either as a neurological condition or as a construct in accounts of behaviour' (Montgomery, 1995, p460). Fatigue has the potential to affect physical performance and mental and emotional status, highlighting the need for research to identify its presentation and functional



impact, the pathophysiological mechanisms behind it and possible management strategies to reduce its effects (Hillier *et al.*, 1997).

One study by Kant, Duffy & Pivovarnik (1998) is relevant as it focuses on apathy, a concept which some might argue is related to fatigue, and is certainly likely to get confounded with fatigue at times. These authors evaluated 83 consecutive patients at a neuropsychiatry clinic with closed head injuries ranging from mild to severe. Severely injured patients were statistically more likely to exhibit apathy alone rather than apathy with depression. Family members tended to rate higher apathy scores than the patients themselves, possibly because of diminished self-awareness following frontal lobe injury on the part of the latter. The authors suggested that the patients' families are often a more valuable resource when attempting to identify an apathy syndrome. It was concluded that a significant percentage of patients with closed head injury were suffering from an apathy syndrome, most frequently alongside a depressive disorder.

It is noted in the above study that no studies have addressed the prevalence of apathy following closed head injury. It is possible that researchers are held back by similar reasons to those preventing investigation into fatigue. It is likely that the dearth of studies relating to fatigue following brain injury results from the complex and subjective nature of fatigue, described above. By way of introduction to the study, therefore, it is necessary to explore literature which although not directly related to brain injury, provides some information on fatigue. The remainder of this section attempts to explore the nature of fatigue by reference to other areas, in which more attempts have been made to study the concept.

## **1.2 OCCUPATIONAL PSYCHOLOGY LITERATURE**

### **1.2.1 Fatigue and performance**

Despite the opinions of Bartley & Chute (1947) and Cameron (1973) that subjective fatigue has no explanatory or predictive power, other authors believe that it is as strongly associated with episodes of poor performance. Hartmann (1967) described the effect of fatigue on performance as an increase in the frequency with which performance deviates beyond acceptable bounds. Neville, Bisson, French, Boll & Storm (1994) note that an association between performance and subjective fatigue has frequently been reported.

### **1.2.2 Shiftwork**

On the whole shiftworkers report more fatigue than day workers (Akerstedt, 1991). It is likely that this is affected by circadian rhythm and sleep loss. Research shows that workers on afternoon/evening shifts sleep longest, workers on day shift sleep slightly less and night shift workers sleep least (Paley & Tepas, 1994). Akerstedt argues that sleepiness during night work may be the result of a combination of rhythmic influences tapping into the circadian rhythm, and homeostatic influences reacting to sleep loss.

Akerstedt's overview suggests that people function more slowly at night and make more mistakes. The early hours of the morning are a common time for accidents to happen (Chernobyl, Three Mile Island reactor accident, the mistakes resulting in the loss of the 'Challenger' space shuttle). Shiftwork is associated with increased subjective, behavioural, and physiological sleepiness – particularly pronounced during the night shift, which can result in falling asleep at work.

### 1.2.3 Nature of work

Finkelman (1994) investigated 3705 employees of a temping agency who reported job fatigue and 10000 who did not. Factors most frequently reported by temporary workers experiencing fatigue were low job challenge and supervision quality. This outcome backed up the traditional research literature in industrial/organisational psychology that has identified many adverse effects associated with poor supervision and lack of challenge on the job. Of the reported cases of fatigue, 96.2 per cent were associated with low information processing demand assignments. Low levels of job control, poor job performance and low pay rates were all significantly associated with the perception of fatigue. Sleep deprivation was found to have minimal impact, although it was probably not adequately evaluated in the survey because the range of working hours was limited.

People in assignments with high information processing demands, high job control and higher pay rates were least likely to report job fatigue. Some of the worst performance was found in people who did jobs where the workload was below a minimal threshold necessary to maintain arousal in a working environment. This is consistent with activation theory where inadequate information processing demands could result in fatigue through diminished arousal, and supports the classic inverted U function of level of arousal and efficiency of performance (Finkelman, 1994).

Grandjean (1979) explains that situations characterised by a low level of stimulation, or regular repetition of identical stimulation, lead to a particular functional state of the central nervous system, characterised by a reduction in the level of cerebral activation.



This is accompanied by feelings of weariness and sleepiness, decreased vigilance, disinclination for the task and decline in alertness.

Davies, Shackleton & Parasuraman (1983) regard boredom as an individual's emotional response to an environment that is perceived to be monotonous and note that little research directly concerning monotony and boredom exists. They refer to early work on this concept: Barmack (1937) divides boredom into a feeling and an attitude, the former associated with low level of physiological arousal, the latter with motivation conflict. This second aspect is graphically described by Fenichel (1934) as arising when we must do what we do not want to do and must not do what we want to do. Alternatively, boredom has been described as a drive which is reduced through divertive exploration and aroused when external stimuli are excessively scarce or excessively monotonous (Kubose, 1972).

#### **1.2.4 Adrenaline/motivation**

Conversely, when a person is very motivated, or the task induces adrenalin secretion, there is some evidence that feelings of fatigue recede. Long distance runners have shown that they can exert considerable control over their own level of fatigue, suggesting some psychological control (Davies *et al.*, 1983). A study focusing on 11 pilots exposed to extended work periods, reduced sleep periods, night work, and circadian dysrhythmia caused by shiftwork and time-zone crossings during Operations Desert Shield and Desert Storm was conducted by Neville *et al.* (1994). They found that increases in 30-day cumulative flight time were not related to increases in fatigue. No evidence was found of a negative effect from the 25-hour extension of the 30-day airlift crew cumulative flight limit. It is notable, however,

that in this study, information from the aircraft's 'black box' revealed that pilot performance may have been endangered by fatigue. Various mistakes made by the air crew are listed in the study, despite the lack of reported fatigue.

## **1.3 THE BRAIN**

### **1.3.1 Arousal**

One part of the brain involved in controlling alertness is the reticular activating system. During deep sleep its level of activity is very low. This increases as sleep becomes shallow and rises steeply on awakening. 'The higher the level of reticular activity the higher the level of alertness, culminating in a state of alarm' (Grandjean, 1979, p177). The two main types of afferent nerve stimuli responsible for activating the structures of the reticular formation are the conscious sphere of the cerebral cortex and the sense organs. Nerve tracts coming from the cerebral cortex carry impulses from the conscious sphere into the reticular activating system. This might occur for example, when something noticed outside seems ominous and calls for increased alertness. Alternatively streams of afferent stimuli from the sense organs enter the reticular activating system, and make it more active. This alerts the cerebral cortex and so ensures that the brain is ready to notice and act on what is happening outside the body. A damping system comprising inhibiting and sleep inducing centres is formed by structures in the thalamus that inhibit activity in the cerebral cortex (Grandjean, 1979). It is possible that damage to these areas of the brain may affect the subjective experience of fatigue following brain injury.

### **1.3.2 Sleep loss**

The major impact of total or partial sleep loss in humans centres on the brain (Horne, 1991). Cerebral function is profoundly affected during sleep loss and 'core sleep', as opposed to 'optional sleep,' seems particularly important for recovery. Horne describes core sleep as that occupying the first three to four sleep cycles. It is dominated by stages three and four sleep (slow wave sleep) and about half of nightly REM sleep. Horne suggests that one reason for the effect of sleep loss on the cerebrum is that they cannot go 'off-line' and relax to any significant extent during wakefulness.

Horne states that the behaviour exhibited in people deprived of core sleep may be similar (but in a far milder form) to that of people who have frontal lobe damage, until that process has been reversed following recovery sleep. In particular he comments on divergent thinking, apathy, increased distractability by irrelevant stimuli, loss of affect in speech, and childish humour, in sleep deprived people. He also notes that few studies of sleep loss have examined people in any systematic way for responses resembling frontal lobe damage, although clear decrements have been found in frontal lobe tests of word fluency, non-verbal planning, creativity and originality, following one night of sleep loss (Horne, 1988). This suggests the possibility of a direct relationship between fatigue and frontal lobe injury.

### **1.3.3 'Worn out' syndrome**

The 'worn out' syndrome was first described by Globus (1969). It was found in a survey of young adults that when sleep length of about 10 hours was not making up for lost sleep, the effect was the worn out syndrome, lasting for four to five hours. Globus uses the following words to describe it: 'worn out', 'lethargic', 'heavy



limbed', 'sluggish' and 'having difficulty in getting going'. Similar findings have followed. Herschovitch, Stuss & Boughton (1980) found that extended sleep affected performance on the Wisconsin Card Sorting Test, which is commonly used in assessing frontal lobe impairment, showing greater forgetfulness and less efficiency. Other studies have found that objective assessments of sleepiness following oversleep did not support an increase in sleepiness, but that participants' subjective experience was that they were very tired (Carskadon, Mancuso, Keenan, Littell & Diment, 1986).

#### **1.3.4 Information processing**

The concept of capacity for information processing is particularly relevant to fatigue following brain injury, as it might be expected that the injury has reduced capacity to perform, thus causing fatigue. Information processing capacity refers to the 'amount of information that can be attended and responded to in a finite period of time' (Sohlberg & Mateer, 1989) and is often equated with attention. Much of the literature relating to this concerns studies where fatigue has been measured in terms of speed of reaction time. Research with brain injured people shows that the speed at which they can respond is reduced in direct proportion to the amount of information that must be processed before a response can be made (Sohlberg & Mateer, 1989; Stuss *et al.*, 1989; van Zomeren & Brouwer, 1987). Writing about post concussional symptoms which included fatigue, van Zomeren & van den Burg (1985) suggested that symptoms resulted from the chronic effort required to cope with persisting cognitive deficits, most particularly reduced speed of information processing.

Similarly, Schmitter-Edgecombe (1996) suggests that the range of performance deficits often exhibited by people following brain injury may be due partially to

deficiencies in some fundamental cognitive abilities involved in the performance of different activities. Maybe following brain injury the amount of available attentional resources or information processing capacity declines, so that people can perform only a limited number of cognitive operations at one time. Automatic processes place modest demands on attention and can be performed without conscious awareness, whereas effortful processes demand active attention and conscious awareness. It is important to note, however, that whilst automatic procedures may require less effort, this should not detract from the possibility that an individual may be using their brain for other activities whilst performing the routine operation. It could be argued that the very nature of a task performed without conscious awareness is that it is a task performed whilst the brain is engaged on another (conscious) pursuit. This is useful to bear in mind when considering the following hypothesis.

Schmitter-Edgecombe suggests that most cognitive operations can be viewed as lying on a continuum between automatic and effortful resource demands. The deficits of brain injured people should be most pronounced when cognitive operations draw heavily on effortful processing resources. Compared to non-brain injured persons, it should take brain injured individuals longer to develop a new automatic process, that is to automatize through practice an effortful process.

In accordance with this attentional resource hypothesis, Montgomery (1995) notes that the management role of the 'frontal brain' diminishes as processes become less effortful and more efficient in a non-brain injured person. If efficient and automatic activation of neural pathways and routines is affected by diffuse lesions following brain injury, familiar cognitive or motor tasks might require unaccustomed



deliberateness and effort, and cause the individual to tire rapidly until automaticity has once again been established.

Supporting evidence for this hypothesis includes the fact that people with severely impaired explicit memory may show normal or near normal implicit perceptual memory skills (Schmitter-Edgecombe, Marks, Fahy & Long, 1992; Spikmen, Berg & Deelman, 1995). Studies using reaction time procedures have demonstrated that the extent of the performance difference between brain injured and non-brain injured groups increases as task complexity increases (Miller, 1970).

Information processing theory, therefore, suggests that fatigue might be expected following brain injury, given the possibility of reduced information processing or attentional resource capacity in the brain. However, Riese, Hoedemaeker, Brouwer, Mulder, Cremer & Veldman (1999) note that complaints of mental fatigue are reported as frequently by people with mild, severe and very severe brain injury, in contrast to cognitive symptoms, which suggests that they are not directly related to brain damage. Riese *et al.* looked at sustained workload in a continuous dynamic divided attention task, which measured performance loss with time on task, subjective reports and cardiovascular measures of mental effort and distress. Their sample included eight severely brain injured people and eight hospital controls. Prior to the experimental conditions being run, single task difficulty was assessed individually and manipulated so that it was assumed to be equally difficult for each participant. Riese *et al.* found that the brain injured people incurred higher psychophysiological costs whilst achieving sustained task performance, and that this finding supported the 'coping hypothesis'. The coping hypothesis suggests that even when task difficulty is

adapted to the cognitive capacities of brain injured individuals, increased effort and distress will still be found.

#### 1.4 FATIGUE AND MOOD

Several studies have noted the presence of depression or anxiety following brain injury (Kant *et al.*, 1998; Jorge, Robinson & Starkstein, 1993; Masson, Maurette, Salmi, Dartigues, Vecsey, Destailats & Emy, 1996).

Burton & Volpe (1994) gave the sickness impact profile (SIP) to 21 brain injured people approximately five years after injury. They found that depression correlated with the physical dimension scales of the SIP but not the cognitive measures. Specific measures of the SIP correlating with depression included sleep and rest, and work. It is possible to see how fatigue might be involved with these measures. The study did not stipulate the sleep and rest that individuals were getting or not getting. However, it is likely that fatigue was involved at some point in this association between depression and sleep and rest. A number of the other physical measures of the SIP which correlated with depression in this study might also involve fatigue, e.g., ambulation, recreation, mobility. If these measures were an effort physically for the brain injured person, this may well have involved feelings of fatigue.

Fatigue is a recognised symptom of depression. It is noted in the description of major depression in DSM IV (APA, 1995) that 'decreased energy, tiredness and fatigue are common' (p321) and that 'a person may experience sustained fatigue without physical exertion' (p321). Sleep disturbance is also linked with depression, most often in the



form of insomnia, although hypersomnia (oversleeping) can also be a symptom. (DSM IV, APA, 1995). Wessely *et al.* (1998) note that fatigue has 'long been considered an integral part of our concept of depression' (p82) and that many epidemiological studies have confirmed its association with lowered mood. For example, a close correlation between results from the General Health Questionnaire (12) and a fatigue questionnaire was found by Pawlikowska, Chalder, Hirsch, Wallace, Wright & Wessely (1994). Christensen & Duncan (1995) found that low energy was more accurate than psychosocial variables in classifying a person as depressed or non-depressed, and Buchwald & Rudick-Davis (1993) that fatigue is the most efficient symptom for correctly classifying depression.

Fatigue is also prominent in anxiety disorders. Together with sleep disturbance and restlessness it forms one of a group of six symptoms, three of which are required to satisfy a criterion for generalised anxiety disorder in DSM IV (APA, 1995). Fatigue, myalgia and sleep disorders are found in the majority of those with generalised anxiety disorder. Fatigue is also associated with an increase in the life time prevalence of panic disorder (Wessely *et al.*, 1998). Buchwald, Sullivan & Komaroff (1987) found that 58 per cent of those in their US primary care sample with substantial fatigue also had anxiety. In a sample of American college students, Montgomery (1983) found associations between fatigue and self reports of both anxiety and depression.

Meltzer, Gill, Petticrew & Hinds (1995) found that fatigue was reported by 27 per cent of the population, while the most common psychiatric diagnosis (mixed anxiety depression) was found in eight per cent. Wessely *et al.* (1998) assert that fatigue is

unlikely to be fully congruent with any particular categorical diagnosis. Although an individual with no psychological symptoms is unlikely to complain of fatigue, and a depressed individual almost certainly will, there is still a large area in between where fatigue exists in combination with other symptoms, but falls short of fulfilling criteria for recognised diagnostic categories (Wessely *et al.* 1998).

Given that both depression and anxiety are common following brain injury, the above findings associating them with fatigue, highlight the complexity around trying to discover more about the subjective nature of fatigue following brain injury.

## 1.5 CHRONIC FATIGUE

Apart from being a symptom of brain injury, plus a range of other conditions, such as cancer (Pearce & Richardson, 1996) and myocardial infarction (Varvaro, Sereika, Zullo & Robertson, 1996), fatigue became a disease in its own right in the 1980's, when the existence of 'chronic fatigue syndrome' (CFS) was formally acknowledged. This followed epidemics of myalgic encephalomyelitis (ME), first mentioned in Britain in 1956 anonymously in the 'Lancet'. Prior to this psychiatrists and neurologists in the mid nineteenth century had identified 'neurasthenia,' later described by Cobb (1920) as a condition of 'nervous exhaustion, characterised by undue fatigue on slightest exertion, both physical and mental'.

Sporadic chronic fatigue syndrome (or ME as it is still referred to) as seen today is non-contagious, chronic, fatiguing and has no neurological signs. The 'Oxford criteria' (Sharpe, Archard & Banatvala, 1992) include a minimum duration of six



months, a definite onset as opposed to lifelong, and functional impairment. The defining characteristic is physical and mental fatigability, with associated symptoms such as myalgia, mood and sleep disturbance. Post-infectious disease is included as a subcategory showing the same features but following a proven infective episode. Psychiatric disorder is not an exclusion criteria as it was previously. Abnormal physical signs are noted to be 'conspicuously absent' (Webb & Parsons, 1991) from CFS although some dispute exists about the existence of softer signs, such as enlarged lymph nodes.

An exploratory study by Schweitzer, Kelly, Foran, Terry & Whiting (1995) on the impact of CFS on everyday physical, psychological and social functioning, involved semi-structured interviews with 23 CFS sufferers. Participants were typically prevented from participating in any physical activities due to the possible exacerbation of symptoms. They were unable to achieve the same quantity and/or quality of work output because of having to rest more often due to physical and mental fatigue. Social activities were also reduced and it was difficult to maintain social relationships. In some instances, the experience of fatigue seemed quite sudden. For example, people would go to work and have to come home early, or they would go out socially but have to return before the end of the evening. Anderson & Ferrans (1997), also investigating the quality of life of people with CFS, reported that all 22 participants in their interview subgroup had found that CFS had impacted on every aspect of their lives in ways they had not imagined possible. Comments included 'It's stopped my life' and 'I spend 21-23 hours of my day lying down' and 'You're exhausted, but can't sleep and can't function, and it never goes away'.

Wearden & Appleby (1997) note that a number of studies looking at cognitive functioning in CFS have found that people generally perform in the normal range on most tests, but that there may be a disparity between the degree of their complaints about cognitive difficulties and the actual decrement in performance. Wearden & Appleby studied two groups of CFS patients, depressed and non-depressed, and healthy controls. After asking participants about difficulties they had in concentrating when reading, they were then given a task in which reading and text recall was measured. It was found that despite all CFS subjects complaining of general cognitive failures and difficulties with reading, only those who were depressed also recalled significantly less than controls, and that severity of complaint about reading was not related to amount of text recalled but to severity of depressed mood.

## 1.6 SUMMARY

Fatigue is a prominent and frequent complaint after brain injury. Despite this very few studies have investigated fatigue in those who have had a brain injury, and where this has occurred it has tended to be in the form of experimental reaction time studies. The preceding sections show that the concept of fatigue has been of interest to researchers in a range of fields for many years. In industry fatigue has been found to be related to boredom, and lack of supervision and control. In more stimulating work, individuals who have been working for a long time without rest may be unaware of mistakes they are making and report low feelings of fatigue. Research focusing on circadian rhythm, has found shiftworkers to feel more fatigued on certain shifts than others, despite their being the same length. Sleep studies show that people may feel fatigued both through lack of sleep and through 'oversleeping', and similarities have

been drawn between the effects of sleep loss and the effects of frontal lobe damage. Fatigue has commonly been linked with depression and anxiety. However, some studies investigating chronic fatigue and mood suggest qualitatively different experiences of fatigue for those suffering from different conditions. Information processing theories have usually been offered as an explanation for increased fatigue following brain injury. However, there are instances where they prove unsatisfactory. The situation is complicated by the fact that brain injured people may suffer depression or anxiety and it is difficult to know to what the fatigue they experience is attributable.

This overview suggests that subjective and objective accounts and measures of fatigue are not always in agreement. Despite the large amount of work relating to fatigue, there remains little associated with subjective reporting particularly in the area of brain injury. Although the findings reported above are interesting, they are less helpful in making any conclusions about fatigue, particularly with regard to brain injury.

### **1.7 AIMS OF THE STUDY**

The focus of this study is to investigate how fatigue is experienced by brain injured people. The problem is approached from both a qualitative and a quantitative perspective. Interviews were conducted with those who had sustained a brain injury to learn about subjective experience, and with relatives to learn about objective signs of fatigue. Measures of fatigue, severity of brain injury, related symptoms, mood and



speed of information processing were administered and quantitative analyses were used to investigate possible associations between these variables.

### **1.7.1 Research questions**

The study asks the following questions of clients:

- a) How do they understand the concepts of fatigue?
- b) How do they describe their subjective experience of fatigue?
- c) Do they feel that their experience of fatigue has altered following their injury?
- d) In what ways, if any, does fatigue impact on their lives?

The study asks the following questions of relatives:

- a) What is their own concept of fatigue?
- b) What signs of fatigue do they observe in their brain injured relative?
- c) Do they feel that the fatigue displayed by their relative has changed following the injury?
- d) In what ways if any do they believe that fatigue has an impact on their relative's life?

### **1.7.2 Hypotheses**

The following null hypotheses are considered in the quantitative analysis:

- a) There is no association between fatigue and severity of brain injury.
- b) There is no association between fatigue and the degree to which an individual is still suffering from brain injury related symptoms.
- c) There is no association between fatigue and mood.
- d) There is no association between fatigue and speed of information processing.

## **PART TWO: METHOD**

## **2.0 METHOD**

### **2.1 DESIGN**

This study is a cross-sectional design. It employs an exploratory approach, as little is known about the experience of tiredness and fatigue amongst people who are brain injured.

Semi-structured interviews were conducted both with the brain injured person and with a close relative. In this way it was possible to learn about the subjective aspects of fatigue from the people who had sustained the injury and objective signs of fatigue from their relatives. The premise of this study is that it was important to address both aspects to gain a better understanding of fatigue. In addition to this qualitative approach, quantitative measures were used to gather other perspectives on the phenomena studied.

Two of the measures related specifically to fatigue and served to triangulate the qualitative information received from client and relative concerning fatigue. Triangulation refers to the process of looking at data from separate sources (Smith, 1995). The other measures concerned mood, symptoms, and speed of information processing, and represented a preliminary attempt to identify any associations between variables. Relatives were asked to complete one questionnaire about their brain injured relative, which concerned symptoms. Quantitative measures were used in a correlational design to investigate possible associations between variables.



## **2.2 PARTICIPANTS**

### **2.2.1 Exclusion and inclusion criteria**

The following criteria were used in the selection of participants:

- a) Participants had to be aged between 18 and 65 years (inclusive).
- b) Participants had to have suffered a *traumatic* brain injury at least one year previously.
- c) Participants had to be able to understand questions and respond to them.

### **2.2.2 Recruitment**

All participants were known to the brain injury rehabilitation service. Initially, 38 letters were sent to those who had been patients in 1996, 1997 and early 1998 who fitted the above criteria, and whose current address was known. Of these, it transpired that two had moved house and their new addresses were not known.

After six weeks a further 26 letters were sent to people who fitted the inclusion criteria. These names were taken from the database of patients who had attended the unit between the years 1992 and 1995.

### **2.2.3 Contacting prospective participants**

The prospective brain injured participants were contacted in the first instance by post. They received a covering introductory letter from the research supervisor (appendix 1). They also received a letter from the researcher (appendix 2), an information sheet about the study (appendix 3), a copy of the consent form so that they understood their rights if they agreed to participate (appendix 4), and an opt-in form (appendix 5). Additionally, the brain injured person received another envelope which they were

asked to pass on to their relatives if they wished them to be involved. This envelope contained an information sheet (appendix 6) and a consent form. Individuals were contacted by telephone only if they returned the opt-in form. Respondents were also given a contact telephone number to call, if they wished to know more about the study. Three people made contact in this way before agreeing to be involved. People responding after a specific date were contacted again in writing and it was explained that because of the time limits of the study it would not be possible to interview them (appendix 7). Because of the length of time between the initial letters being sent and the limiting date, this only occurred in one instance.

#### **2.2.4. Response rate**

Of the 62 people with brain injury contacted, 22 responded, indicating a response rate of 35 per cent. Of these, one person did not have a contact telephone number and when contacted again by letter did not respond, and one person responded outside the time limit of the study.

### **2.3 ETHICAL CONSIDERATIONS**

Prior to commencement of the study, full ethical approval was obtained from the appropriate local research ethics committee (appendix 8). Prior to interviewing, the researcher answered any questions individuals had about the study and then collected the consent form from them. A debriefing question followed all interviews, which gave people the chance to discuss any issues that had been raised for them during the interview process. Participants were also given the option of having their GP informed of their participation in the study if they wished (appendix 9).

## **2.4 DEMOGRAPHIC INFORMATION**

This was obtained in a short structured interview with the brain injured person prior to the main interview (appendix 10). If they were unsure of answers to some questions, relatives were asked.

### **2.4.1 Gender**

Because brain injury is much more commonly seen amongst men it was not feasible to recruit equal numbers of men and women. Altogether, 16 brain injured men and four brain injured women took part in the study.

### **2.4.2 Nature of accident**

Fourteen people had been involved in road traffic accidents. Of these, six were driving at the time of the accident, five were passengers, two were cycling, and one was a pedestrian. Three people had been assaulted, and three had had a fall. Of those who had fallen, one person fell because of a fit, one lost his balance and one attempted suicide. Age ranged from 19 to 62 years at the time of the interview.

### **2.4.3 Length of post traumatic amnesia (PTA)**

PTA is generally considered to be the most accurate measure of severity of brain injury. It refers to the length of time between point of injury and return of continuous day to day memory. This varied from four days to 135 days. Thus, all injuries counted as severe, although some were clearly more severe than others.



#### **2.4.4 Work**

At the time of interviewing, three people were working full time, three were working part time, three were doing voluntary work, four were at college part time, one was involved in childcare, and six were not working.

#### **2.4.5 Relatives/close friends**

Two brain injured people did not have a suitable relative who could be involved in the study. Eight people involved their parents, and 10 people involved their partners.

### **2.5 QUALITATIVE QUESTIONS**

One set of qualitative questions were asked to the brain injured person about themselves (appendix 11). A comparable set of questions was asked of relatives about the brain injured person (appendix 12).

A semi-structured interview seemed important because while it gave the respondent the opportunity to describe their own experience, it also enabled the researcher to explore aspects of fatigue which have been documented in other contexts. Additionally, because a brain injury can sometimes make it difficult for an individual to allow their thoughts to keep on track, it seemed important to use the same prompts for each person if they were required.

The open questions were devised from two main sources. The research supervisor and researcher discussed the type of question that might be appropriate in ascertaining the individual's experience of fatigue, and the conditions which exacerbated it.



Questions were also generated from reading related literature on fatigue in the areas of work, sleep, chronic fatigue, and mood.

### **2.5.1 Evaluation of qualitative findings**

Three concepts were used to guide evaluation of the qualitative questions. These are outlined below.

**2.5.1.1 Respondent validity** Respondent validity refers to participant agreement with the researcher's interpretations. To achieve respondent validity, four individuals were sent a summary of the researcher's understanding of their perceptions of fatigue. One of these letters can be seen in appendix 13. They were telephoned one week later and asked to comment on the accuracy of the summary. These four people had of their own volition indicated at interview that they would be prepared to be involved further if necessary. Each of these people agreed that they had been sent an accurate summary of their views. One person wished to add something which he was aware he had not said when interviewed. Respondent validity will be further explored by inviting feedback from participants when they have received a summary sheet of the study's findings (currently being prepared).

**2.5.1.2 Inter-rater reliability** Inter-rater reliability was assessed in two stages. Firstly, an independent rater analysed twenty interviews, and categories were compared with those of the researcher (appendix 14). There was a strong measure of agreement, although a minority of categories had been broken down further in some instances by one or other of the raters. Secondly, four sets of categories gathered under research questions or broad themes emerging from the research were given to the independent

rater together with 10 to 20 quotes for each set. The independent rater then coded the quotes under the categories and these were then compared with those of the researcher. Appendix 15 shows one of these sets of quotes. Concordance on this measure was 100 per cent.

**2.5.1.3 Auditability** Auditability refers to being explicit about how findings are derived, by allowing others to follow the same steps. A detailed description of the procedure used is documented in section 2.8.1. A sample of the coding of quotes for inter-rater reliability is also available for scrutiny in appendix 16.

## **2.6 QUANTITATIVE MEASURES**

### **2.6.1 Background information**

This was gathered in the initial structured interview. This ascertained the age of the brain injured person, date and nature of injury, length of PTA and enduring problems arising from the injury.

### **2.6.2 Speed of information processing task**

A task comparable to that found in the Adult Memory and Information Processing Battery (Coughlan & Hollows, 1985) was used in the study (appendix 17). The participant was asked to delete the second largest number in a row of five, and to work accurately through as many of these tasks as possible until asked to stop. The participant was given four minutes to complete as much of the task as they could. The total number of items attempted was used as the overall score.

### **2.6.3 Visual analogue scales**

Two visual analogue scales were devised by the researcher in consultation with the research supervisor to be used as a guide to give an overall indication of how much fatigue and tiredness were seen as a problem to the individual. Each scale assessed individual perceptions of severity of fatigue. The first was concerned with how much of an impact tiredness and fatigue had on the person and the second was phrased in terms of how often the person felt tired or fatigued (appendix 18). Each scale was 10 centimetres long. A single stroke marked the centre of the line to assist any participants with impaired spatial perception. On the first scale, answers indicating higher levels of fatigue occupied the right hand end of the line, and on the second scale answers indicating higher levels of fatigue occupied the left hand end. In this way some degree of reliability could be assessed by comparing an individual's responses.

### **2.6.4 Fatigue Assessment Instrument (FAI) (Schwartz, Jandorf & Krupp, 1993).**

This checklist has 29 items with 7-point scales and is designed to capture both quantitative and qualitative components of respondents' fatigue (appendix 19). Although designed for people with fatigue as a major presenting symptom, the authors also state that it can be given to controls 'since to some extent fatigue is a universal experience' (Schwartz *et al.*, 1993). The items for this checklist were generated from clinical experience and information collected in a series of interviews with 25 patients experiencing fatigue. Validity was investigated by administration to six patient groups where fatigue was a recognised secondary symptom and to a group of controls. Factor analysis identified four distinct dimensions of fatigue underlying the items in the checklist: fatigue severity (11 items), situation specificity (6 items),



psychological consequences of fatigue (3 items) and response to rest/sleep (2 items). The corresponding sub-scales for measuring these dimensions exhibited good to excellent internal consistency ( $\alpha = 0.70-0.92$ ). Convergent validity was examined by correlating the sub-scales with two other fatigue measures, and the results were reported to be consistent with the intended purposes of the other two scales. Test-retest reliability was described as moderate. The authors argued that this underestimated the true reproducibility of the instrument because of the natural waxing and waning of fatigue symptoms. However, it was also felt inappropriate to perform test-retest correlations on very short intervals, as these were likely to be inflated due to memory effects. Despite this difficulty, test-retest reliability was stated to be 'similar to that reported from other fatigue related measures'.

This scale was chosen in preference to other scales (e.g., Chalder, Berelowitz, Pawlikowska, Watts, Wessely, Wright & Wallace, 1993) where items could be easily confounded with direct consequences of brain injury, or where the scale was too long (e.g. Piper, Lindsey, Dodd, Ferketich, Paul & Weller, 1989).

In the present study, the four sub-scores corresponding to the four dimensions emerging from the factor analysis were calculated and correlated. Further details of this process and the decision to use a single scale are given in the results section.



### **2.6.5 Wimbledon Self Report Scale (WSRS) (Coughlan & Storey, 1988)**

This scale has the advantage of having been designed specifically for people with neurological conditions including brain injury, and focuses on emotional and mood appraisal (appendix 20). It addresses problems and ability to participate in or enjoy former activities.

The WSRS comprises 30 adjectives and phrases describing feelings, 24 of which are unpleasant and six pleasant. The participant is asked to rate each item for its pervasiveness in the past week on a four-point scale. The test-retest reliability of the WSRS was assessed by Coughlan & Storey by re-administering the scale to 40 patients on neurological and psychiatric wards no less than four hours later on the same or the next day. This produced a highly significant correlation (Spearman rank correlation,  $p < .001$ ). The WSRS was validated by comparison with psychiatric assessment, administration with depressed psychiatric patients and a general population sample.

For the unpleasant feelings, the ratings are (a) most of the time; (b) quite often; (c) only occasionally and (d) not at all. For pleasant feelings the order is reversed. Responses (a) and (b) score one and (c) and (d) zero. Scores of zero to seven are considered to be within normal limits; scores of eight to ten as borderline, and scores of 11 to 30 as reflecting clinically significant mood disturbance.

### **2.6.6 Injury related symptom checklist**

This 75 item checklist is concerned with frequency of behaviour, memory and reasoning problems following brain injury (appendix 21). Scores are derived from

ratings of one to four, where one stands for 'almost never' and four for 'almost always'. It has been developed from the scale reported by Oddy, Humphrey & Uttley (1978) and Oddy, Coughlan, Tyerman & Jenkins (1985). It was given both to the brain injured person and to their relative (appendix 22).

In the present study the scores were derived from adding the ratings of one to four selected by the respondent. Split half reliability was calculated on those forms completed by the brain injured participants. The correlation was highly significant (Spearman's rho,  $\rho = .9257, p < .001$ ).

## **2.7 PILOT STUDY**

The interview and each measure were piloted on an individual with a diagnosis of chronic fatigue syndrome. Someone suffering from a different condition was chosen because initially there were concerns about obtaining a large enough sample of brain injured people for the study. Minor changes were made to the researcher's prompts in the qualitative interview schedule following the pilot.

## **2.8 PROCEDURE**

Following receipt of the opt-in forms, telephone contact was made with participants and a time agreed for the researcher to visit them in their own homes. Upon arrival, both the brain injured person and their relative were asked to complete a consent form if they had not done so already. Unless participants requested otherwise, interviews were carried out separately to ensure that one respondent was not influenced by the

other. The brain injured person was interviewed first. At the end of the interview, the participant was given the speed of information processing task. They were then introduced to the set of questionnaires and asked to complete them in a different room. This meant that they were free to interpret the questions without interviewer bias. While they were doing this, their relative was interviewed and was then asked to complete the injury related symptom checklist.

## **2.9 ANALYSIS**

### **2.9.1 Qualitative analysis**

Semi-structured interviews were analysed using a grounded theory approach, which is suitable for use with any unstructured material (Henwood & Pidgeon, 1995). The central idea of grounded theory is that theory is generated from and grounded in data by a process of induction (Glaser & Strauss, 1967). Theory generation rather than verification is thus the ultimate aim of the grounded approach (Glaus, Crowe & Hammond, 1996). However, Henwood & Pidgeon (1995) recognise that it may not always be possible to realize such an ambitious goal. They state that it is possible to specify a variety of research activities which can be achieved through grounded theory, but which do not require the building of a total theory.

Each interview was transcribed onto the computer. The material was read and then re-read. 'Categories' were pencilled into the left hand margins of each interview transcript. For the purposes of this study a category may be described as a word or short phrase summarising a point made by the participant. The content of each interview was then reorganised on the computer under various 'themes'. A theme in this study describes a higher level of abstraction than a category, under which more

than one category may be subsumed. This aspect of the analysis was guided in part by the open questions, although some themes were generated by the material. Categories and themes were then considered across the interviews and the number of respondents describing a particular category was recorded. It is important to note however, that while attention was given to number, categories common to one individual alone were also considered to be valuable parts of the data.

Interviews of those who had sustained the injury and those of their relatives were kept separate throughout the analysis.

### **2.9.2 Quantitative analysis**

The nature of much of the data set obtained is ordinal. Because most of the data did not meet the criteria for parametric analysis, non-parametric statistics were used throughout.

The first stage of quantitative analysis employed Mann-Whitney tests to explore the relationship between the different measures of subjective fatigue.

Inspection of the qualitative data suggested that individuals' experience of fatigue varied along a continuum rather than either as highly severely or not at all. For this reason, and to avoid 'losing' any data by collapsing variables into groups, Spearman's rho correlations were performed on the sample as a whole. Analyses focused on determining whether associations existed between subjective fatigue and injury severity, symptoms, mood and information processing speed. SPSS for windows (1995) was used to carry out these analyses.



## **PART THREE: RESULTS**

### 3.0 RESULTS

#### 3.1 MEASUREMENT OF FATIGUE

##### 3.1.1 Fatigue assessment instrument

Factor analysis of the FAI suggests four sub-scales by which to consider different aspects of fatigue (Schwartz *et al.*,1993). These include fatigue severity, situation specificity, psychological consequences of fatigue and response to rest/sleep.

Different factors on the FAI were correlated (Spearman's rho, two-tailed) and significance levels are shown in Table one.

Table 1 Correlations (Spearman's rho) between factors on the FAI

(N = 20)	Situation specificity	Consequences of fatigue	Response to rest /sleep
Fatigue Severity	$p = .014$ $\text{rho} = .5411$	$p < .001$ $\text{rho} = .7084$	$p < .001$ $\text{rho} = .7202$
Situation specificity	-	$p = .083$ $\text{rho} = .3974$	$p = .025$ $\text{rho} = .4981$
Consequences of fatigue	-	-	$p = .003$ $\text{rho} = .6268$

With the exception of situation specificity and psychological consequences of fatigue, all other correlations between factors were found to be significant. Fatigue severity is the most global factor (Schwartz *et al.*, 1993) and also the one informed by the most questions from the questionnaire. For this reason and because of restricted space, this factor alone will represent results from the FAI in the analyses that follow.

### 3.1.2 Visual analogue scales

It was hypothesised that the visual analogue scale 'Tiredness/fatigue has a major impact on my life – tiredness/fatigue is not a problem at all for me' would correlate negatively with the visual analogue scale 'I rarely feel tired/fatigued – I almost always feel tired/fatigued'. This was found to be significant (Spearman's  $\rho = -.7158$ ,  $p < .001$ , two-tailed). This showed consistency in individuals across the two scales.

### 3.1.3 FAI and visual analogue scales

A high score on fatigue severity was found to correlate significantly with reported impact of fatigue on everyday life (Spearman's  $\rho = -.6730$ ,  $p = .001$ , two-tailed) and with how frequently an individual felt tired or fatigued (Spearman's  $\rho = .7618$ ,  $p < .001$ , two-tailed).

Because the fatigue severity measure is more global, based on 11 different aspects of fatigue, a decision was made to use this rather than the visual analogue scales in the remainder of the analyses.

### 3.1.4 Reports of fatigue in the interviews

In the interviews eight people stated clearly that fatigue was a problem. Eight people also stated clearly that fatigue was not a problem. The remaining four were less clear: For example one person said,

*'tiredness doesn't stop me doing things, but I am slower in everything I do'.*

Another person said:

*'Tiredness doesn't stop me really.'*

but also said

*'It is actually a problem to me as it might have been an actual physical injury, but it is something I actually have to tackle and get over in my attempt to rejoin the human race.'*

For the purposes of triangulating the data on subjective fatigue only, responses from the interviews were divided into the groups described above and compared with responses on the visual analogue scales, and fatigue severity scores from the FAI using Mann-Whitney tests. Table two shows the results.

**Table 2 Comparison of measures of fatigue using Mann-Whitney tests**

Pairs of groups	Fatigue severity scores	Visual analogue scale: impact of tiredness/fatigue	Visual analogue scale: frequency of tiredness/fatigue
Group 1 (N=8) (fatigue is a problem) and Group 2 (N=4) (fatigue may be a problem)	U = 6.5 $p = .1054$ (2-tailed)	U = 2 $p = .0172$ (2-tailed)	U = 1.0 $p = .0107$ (2-tailed)
Group1 (N=8) (fatigue is a problem) and Group 3 (N=8) (fatigue is not a problem)	U = 6.5 $p = .0073$ (2-tailed)	U = 7.5 $p = .0099$ (2-tailed)	U = 1.0 $p = .0011$ (2-tailed)
Group 2 (N=4) (fatigue may be a problem) and Group 3 (N=8) (fatigue is not a problem)	U = 8 $p = .1742$ (2-tailed)	U = 13.0 $p = .6079$ (2-tailed)	U = 9.0 $p = .232$ (2-tailed)

This confirms that people who stated clearly that fatigue was a problem, scored significantly worse on the fatigue severity scale and visual analogue scales.

### 3.2 QUANTITATIVE ANALYSIS OF THE DATA

Despite the above findings, as already noted in the method, inspection of the qualitative data suggested that individuals' experience of fatigue varied along a continuum rather than either as highly severely or not at all. Correlations were therefore performed on the sample as a whole.



### **3.2.1. Null hypothesis 'a': There is no association between tiredness/fatigue and severity of brain injury**

Correlation of length of PTA with scores of fatigue severity produced no significant association (Spearman's  $\rho = -.2154$ ,  $p = .362$ , two-tailed). The null hypothesis was not rejected.

### **3.2.2 Null hypothesis 'b': There is no association between tiredness/fatigue and the degree to which an individual is still suffering from brain injury related symptoms**

Nineteen of the 20 brain injured participants completed the symptom checklist. Three people did not complete all 75 items, although no one completed less than 72. Because not everyone had completed all items, scores were converted into percentages to standardise the results. Correlation showed a significant association between symptoms and fatigue severity (Spearman's  $\rho = .7254$ ,  $p < .001$ , two-tailed) and the null hypothesis was rejected. Relatives also completed the checklist with their views of their relatives' symptoms. Correlation of relatives' and brain injured participants' views was significant (Spearman's  $\rho$ ,  $\rho = .5783$ ,  $p = .015$ , two-tailed). However, relatives' impressions of symptoms was not significantly associated with brain injured participants' subjective experiences of fatigue severity (Spearman's  $\rho$ ,  $\rho = .3934$ ,  $p = .106$ , two-tailed).

Neither brain injured participants' nor relatives' checklist scores were significantly correlated with duration of PTA (Spearman's  $\rho$ ,  $\rho = .0207$ ,  $p = .933$ ;  $\rho = .2924$ ,  $p = .239$ , respectively).

### **3.2.3 Null hypothesis 'c': There is no association between tiredness/fatigue and mood**

Scores on the WSRS were correlated with scores of fatigue severity. Spearman's rho correlation was significant (Spearman's rho = .5680,  $p = .011$ , two-tailed) showing that the lower the individual's mood state, the higher their reports of fatigue severity, and the null hypothesis was rejected.

### **3.2.4. Null hypothesis 'd': There is no association between tiredness/fatigue and speed of information processing**

Scores on the speed of information processing test were not significantly associated with scores of fatigue severity (Spearman's rho = -.0716,  $p = .771$ , two-tailed). The null hypothesis was not rejected.

## **3.3 QUALITATIVE ANALYSIS OF RESEARCH QUESTIONS**

Because of limited space, reporting of qualitative findings focuses on the interviews conducted with those who had sustained a brain injury. A smaller section on findings from relatives' interviews then follows.

### **3.3.1 How would you describe tiredness/fatigue?**

Categories generated from answers to this question and their frequency are shown in Table three.

Table 3 Properties of fatigue, described by people with brain injury

Tiredness/fatigue is...	Number of people
Mental and physical	12
Apathy/lack of motivation	10
Sleepiness/desire for rest	8
Decreased performance/slowness	5
Exhaustion	4
Lack of energy	2
Lack of clarity	2
All physical	2
All mental	2
Decreased agitation	1
Controlled by the mind	1

An over riding theme in response to this question seemed to be whether people regarded fatigue as mental, physical or both. Although 12 people felt that fatigue was both a mental and a physical state

*'I suppose, lack of physical energy, moving about. I suppose the other type is lack of mental energy',*

some comments reflected a feeling that fatigue was predominantly mental:

*'my feeling is that its more mental application than physical'.*

Others were adamant that it was either physical or mental:

*'it's not physical, it's all mental'*

*'it's only physical as far as I'm concerned.'*

Another broad theme included the idea that fatigue slowed you down in some way or another. Fatigue was seen as a state of sleepiness or a need to rest:

*'just feeling tired, sleepy'*

*'having to sit down and rest'*

Some comments related specifically to slowness and reduced efficiency:

*'it's a clouding over of the brain'*

*'it's the inability to perform procedures in your usual manner'.*

People also described a lack of motivation:

*'you don't really want to do anything'*

*'you can't motivate yourself to do anything, even to think, yes especially to think'*

### 3.3.2 How do you feel/know when you are tired/fatigued?

Table 4 shows the different signs and feelings of fatigue experienced by brain injured participants.

**Table 4 Awareness of fatigue by people with brain injury**

How do you feel/know when you are tired/fatigued?	Number of people
Concentration impaired/attention wanders	10
Yawning/sleepiness/nodding off	9
Get irritable/short-tempered	8
Eyes get heavy	7
Can't use my head/think	7
Muscular aches and pains	4
Headache	4
Speech affected	4
Clumsy/uncoordinated	2
Memory gets worse	2
Feel vulnerable	2
Feel anxious	2
Feel depressed	2
Start slumping	1
Physical slowness	1
Aware that energy level is low	1

The experiences listed in Table 4 may be divided into broad themes of physical, mental and emotional signs and experiences of fatigue. Physical signs of fatigue included, for example,

*'and when I'm feeling tired I feel as if I've got a tight band round my head, from the base of the neck round.'*

Experiences of mental fatigue included:

*'Like you read a passage, and then you realize you haven't taken it in, so you try it again and again and again and so you just give up.'*

References to emotional signs of fatigue were mostly related to becoming irritable or



losing one's temper:

*'And you slowly learn through recovery how to get back to your old personality, but that is - you still have to focus on that all the time and if you get tired you can't focus on it as much, so you revert back to - like me, I get angry when I'm tired.'*

Three people said that they were not always aware of their fatigue creeping up until it suddenly hit them. Three people said that their fatigue was sometimes pointed out to them by other people who suggested that they should go and lie down.

While Table four gives some idea of the overlap of feelings experienced by people when they are fatigued, the following quotes are particularly descriptive:

*'I can't think quick enough, I can't talk properly and the brain starts to get very, as though its going to shut off any minute.'*

*'I think as I become more tired my ability to do anything becomes less'*

*'The tired feeling makes everything that you use your head for, your brain for, slower, and it makes you feel like you're trying to think your way through porridge, or through something that's thick and you can't see very far, you can't find anything very easily'*

*'It's like a severe case of sleep deprivation... and it's that feeling of disorientation, lethargy and depression and all that that entails.'*

In addition to experiencing particular feelings when tired, another theme concerned feelings regarding fatigue. Four people commented on the frustration that they felt with their fatigue:

*'The frustrating thing is having to rest'*

*'It can actually make you feel frustrated at times'*

Three people talked about how irritated it made them:

*'It is a mega nuisance though, it really is'*

Only one person commented that fatigue could be pleasant at times, whereas five commented that it was always unpleasant.

3.3.3 Are you on any medication?

Because of the more concrete nature of this question (and some of those which follow) it did not seem appropriate to extract broad themes from peoples’ responses, which remained as categories. Table five shows the medication people were on.

Table 5 Number of people on medication

Medication	Number of people
Antidepressant only	4
Anticonvulsant only	2
Antipsychotic only	1
Antidepressant plus anxiolytic	1

Three people did not identify fatigue as a problem. Those who were on antidepressants only described fatigue as a major problem. One person said:

*‘I feel an utter failure actually every day - in being a wife, I can no longer hold a job down, organise when anyone’s coming. I can’t do things as I used to do and I never think of things or people’s feelings like I used to.’*

Another of these four described a depressive component to his experience of fatigue, saying for example,

*‘Too much effort is required which reflects just the general sense of tiredness and fatigue that you’re going through.’*

This participant felt that his lack of motivation was caused by a mixture of fatigue and depression. Another noted that he was unsure how much he actually felt fatigued and sleepy and how much was to do with going to bed when he couldn’t face everyday life. Anxiety also seemed to be a problem for this person, although he was not on any anxiolytic medication. He talked about fatigue sometimes resulting from worrying about things that might happen, rather than things that would happen and what he might have to do to sort them out.

*‘Being tired after a quite simple task, or even the thought of doing the task. More thinking about it than actually doing the task itself.’*

The person on an antidepressant and an anxiolytic described fatigue both as a problem and not as a problem at different times during his interview. It is notable however, that he talked very clearly about the role of anxiety in his fatigue.

*'I suppose logically thinking it's anxiety that tires me out. I've got all the mental stress and strain with what I've got to achieve and not enough time.'*

The anticonvulsant drug phenytoin is not associated with fatigue or drowsiness (British National Formulary (BNF), 1999). The antidepressants people were on (e.g., sertraline, fluoxetine) are noted to be 'less sedating' (BNF, 1999, p188) than other antidepressants. One person commented that he had changed his antidepressant because he thought it might be making him drowsy. Side effects of anxiolytics may include drowsiness (BNF, 1999). The side effects of the antipsychotic (risperidone) include insomnia, drowsiness and fatigue (BNF, 1999) although the person on this drug slept well and did not complain of fatigue.

**3.3.4 How well do you sleep?**

Table six shows the number of hours brain injured participants slept for during the night.

**Table 6 Number of hours slept during the night by participants with brain injury**

Hours slept	Number of people
4	1
5	1
7/7.5	3
8/8.5	6
9/9.5	5
10/10.5	3
11	1

When asked about the quality of their sleep, three people described it as poor, nine as variable and eight as good. Three people commented that their sleep was not always refreshing:

*'Going to sleep doesn't necessarily fill me with freshness, energy, whatever.'*

Ten people also slept during the day. Daytime sleep varied from having a quick nap in the afternoon if unoccupied, to a strict regime of having a specific sleep scheduled to enable the individual to get through the day:

*'It will continue at home if I don't have a rest.'*

A broad theme to emerge from this question was that many people spent more time sleeping over 24 hours than might normally be expected.

**3.3.5 Are there specific times when you feel tired/fatigued?**

Table seven shows times of day that people felt most fatigued.

**Table 7 Times of day when people with brain injury were most likely to feel fatigued**

Times of day when tiredness/fatigue most apparent	Number of people
Mid afternoon	7
Evening	5
Morning	3
Lunch time	3
Late afternoon/early evening	3
No particular times	3

Answers produced several themes that seemed to influence times of tiredness. These included daytime sleep, activity, the accumulation of fatigue, the permanence of fatigue, and lifestyle.



For some people, times of tiredness were affected by whether they were approaching a time when they were due for a sleep. If a sleep was missed they would then feel tired for the remainder of the day. Four people said that it depended what they had been doing.

*'it does usually come on if I've had a busy day - like if I've had a full day at college.'*

Five described their fatigue as something that accumulated as the day went on and two people commented that it was worse at the end of the week.

*'especially after work – the first hour indoors is the hardest.'*

*'If I've had a busy week, I'm tired by the end of it – and I only work four days at the moment.'*

One person explained that although fatigue always got progressively worse during the day, and he always felt incapacitated by the end of the day, some days were better than others:

*'You get good days and bad days.'*

Others commented on the permanence of fatigue:

*'I seem to feel tired all the time at the moment.'*

*'I'm aware of it all the time'.*

Three people said that there wasn't a particular time of day when they felt tired. One person talked of his changed lifestyle by way of explanation

*'...I don't have commitments. I can be relaxed about when I am sleepy and when I am not.'*

This change in lifestyle did seem relevant to some people who did not report difficulties with fatigue, particularly given the comparatively long hours slept over a 24 hour period.

3.3.6 Are there particular situations when you feel tired/fatigued?

A variety of overlapping and contrasting situations were associated with fatigue, as can be seen in Table eight.

Table 8 Situations commonly associated with fatigue by people with brain injury

Situations associated with tiredness	Number of people
Inactive, boring situations	10
Being busy (work, study)	8
Social situations	6
Anxiety provoking, stressful situations	6
No particular situations	5
Being in pain/recovering	3
When things get complicated	2
Unfamiliar situations	1
Drinking alcohol	1

One broad theme emerging from responses included fatigue being associated with mentally or physically demanding activity. Comments on mental activity included:

- 'Anything that is difficult and requires thought, or is complicated, then it's more tiring.'*
- 'Just when things seem to get very complicated, it's more degree of complicated, how complicated things are and how muddling they are.'*
- 'If I'm not understanding...so if I'm in an exam, then I'm likely to feel really tired.'*

Comments made about physically demanding situations are more complicated as some people were clearly affected by physical injuries they had sustained. However, this was not always the case:

- 'If I try mowing the lawn for my dad or something, I'm sure I'm far more tired afterwards than I was before I got the head injury.'*

Social situations also caused problems for people:

- 'I went to the pub with a friend, and was absolutely exhausted at the end.'*
- 'I felt as if there was cotton wool around me, that I wasn't quite hearing everything that was being shared.'*

At times this seemed to be linked to anxiety associated with the situation:

*'Meeting people, particularly strangers, I think it's more stressful, so I think stress is what affects it most.'*

*'If I wasn't tired I don't think I'd be afraid to go and meet people.'*

It seems likely that a number of situations, for example, being at work, might include more than one of the above categories. One person said for example:

*'At work if I'm under a lot of pressure – if something's got to be done, I may notice it then.'*

This might incorporate mental or physical exertion, social interaction, and anxiety about getting the job done.

In contrast, unstimulating, boring situations were also reported to lead to fatigue.

*'If I had something to do it wouldn't bother me.'*

*'Tiredness could be linked with boredom. I don't get bored with work. I get bored sitting around. That's when I feel more tired.'*

While some people commented on active situations alone and others on unstimulating situations alone, it is notable that a number of individuals found that both types of situation brought on fatigue. This may link with comments reported in the previous section about feeling tired all the time.

### **3.3.7 What do you think the causes of your tiredness/fatigue are?**

All eight people who had clearly stated that fatigue was a problem for them, felt that their injury was the cause of their fatigue.

*'I don't ever recall being tired before my injury.'*

Others also stated that brain injury was the cause of increased fatigue. Three of these people belonged to the group who seemed to have mixed feelings about whether or

not fatigue was a problem for them. The fourth person from this group noted that his injury had led to poor sleep.

Two people who had stated that fatigue was not a problem for them, also agreed that their brain injury was the cause of their fatigue. For one person this was linked to the fact that fatigue had initially been a problem for him following his accident, but was no longer. The other person experienced fatigue in bursts. While he did not class fatigue as a problem, nevertheless he attributed the sudden bursts of fatigue to his brain injury.

Thus, the broad theme emerging from this question was that everyone blamed their brain injury for any undue fatigue.

**3.3.8 Do you think that the amount of tiredness/fatigue you experience has increased, stayed the same, or decreased following your injury?**

Table nine shows whether fatigue levels had changed since the injury.

**Table 9 Perceived change in fatigue following injury**

Changes in level of tiredness/fatigue since the injury	Number of people
Tiredness/fatigue has decreased	12
Tiredness/fatigue has stayed the same (was never a problem)	4
Tiredness/fatigue has stayed the same (has not got any better)	2
Tiredness/fatigue has increased	2

Although the majority of people found that their fatigue had improved since the injury – if indeed it had ever been a problem,

*'It's getting better gradually',*

*'Wore off in dribs and drabs over a longish period',*

others felt that there had been no improvement:



*'I think I've come to understand it. It's just the same. I don't think it's got any less.'*

*'I keep thinking it'll get better and it just doesn't.'*

Others still, felt that it had actually got worse. It is possible that this was related to becoming more active as convalescence progressed:

*'It's increased. In hospital I didn't have tiredness. I was resting all the time.'*

*'It's got worse since the accident. I went back to work for a couple of years and during that time it got worse. I became more easily tired, more easily fatigued.'*

Whether or not improvement was reported did not seem to be related to the year of the injury. The injuries of those who felt it had improved ranged from 1995 to 1998. Those who felt it had stayed the same were injured in 1992 and 1994. Those who felt that their fatigue had become worse were injured in 1994 and 1996.

Some people commented on their expectations for the future. Table 10 shows how participants were divided in their expectations.

**Table 10 Expectations regarding change in fatigue in people with brain injury**

Expectations for change in tiredness/fatigue	Number of people
Don't know	4
Fatigue/tiredness will continue to improve	3
Fatigue/tiredness will stay the same	3

Clearly this was not an issue for those who did not see fatigue as a problem, although one person commented that his fatigue had improved in recent months and reached a stage where it was no worse than it had been prior to his injury.

One person who felt that her fatigue would not improve more, said

*'It's levelled off. I hope it gets better, but I can just see it getting worse.'*

Others were more hopeful:

*'I've been told its five years, you can improve till then.'*

One person expressed uncertainly about future improvement particularly graphically

*'It's like looking into a cloud – you can see the end result of what you want – but how to get there? It's like driving through fog isn't it really?'*

**3.4. QUALITATIVE ANALYSIS OF ADDITIONAL INTERVIEW MATERIAL**

**3.4.1 Energy levels**

A number of people commented on change in energy levels following the injury, as can be seen in Table 11.

**Table 11 Change in energy levels following brain injury**

Change in energy level	Number of people
I have less energy to get through the day	7
It takes more effort/energy to do the same task	7
Recovery period is longer	3

This broad theme focused on reduced energy or more energy being needed to achieve a task. A number of people talked about having limited energy:

*'Energy is kind of like money – I wouldn't spend it all at once first thing in the morning, because I want to last all day.'*

*'If I don't do much then I'm alright.'*

*'I normally have to come home and have a couple of hours kip before I do anything else.'*

Some people made it explicit that getting through a day was exhausting in itself:

*'Now it hits me when I am doing every day things...The very fact that I am awake now for a length of time is tiring.'*

*'I am just amazed at the amount of energy one needs to conduct a normal day.'*

Comments about needing more effort to do the same tasks included:

*'It takes longer to do the accounts and read and pick up the thread....Possibly I feel more tired at the end'*

*'Everything's a bit harder as well. Everything seems, maybe it's just the way I've had to work the last couple of years. I'm having to concentrate a lot more.'*

In some ways this seemed related to increased slowness following the injury:

*'I did maths A level last year and I had extra time because of my injury – four hours - so after that I was just brain dead.'*

*'But I am slower in everything that I do. Physical, mental, even driving I don't drive as fast – I'm concentrating more whereas before I done things naturally, now I have to think about things. Take it as learning everything again – driving and concentrating on everything around you.'*

Greater effort and greater slowness seemed to also link in with a theme concerning reduced information processing capacity. Five people made reference to this, with comments such as:

*'I can only ever focus on one thing at once'*

*'trying to do more than one thing gets me into a real state'*

Comments on recovery rate included:

*'Oh yes, the recovery rate is very slow. In other words, before my accident, if I got tired, just natural activities, I'd go to sleep and feel fine in the morning – a good night's sleep would be OK and take care of everything. Now that's not the case.'*

*'Once last week I went out and saw my friends and stayed out till one. And the rest of the week it knocked me sideways – couldn't cope – couldn't handle anything.'*

### 3.4.2 Motivation and strategies

Some people were clearly more motivated than others to work at reducing their fatigue levels. It was notable that motivation did not necessarily relate to decreased fatigue. Some people who complained of the most severe fatigue had strategies in place to help them combat it. These categories subsumed under the theme of strategies are shown in Table 12.

Table 12 Strategies of people with brain injury to help combat fatigue

Strategies for combating tiredness/fatigue	Number of people
Rest every day	7
Keep active, don't think about it	4
Ration energy	3
Build stamina up	1
Push oneself	1

Scheduling rest or sleep into the day was a popular way to try to control fatigue:

*'I wear a timer that goes off every hour and when it goes off I stop what I'm doing and I sit down for at least half an hour.'*

Some people were keen to ration their limited energy or to make best use of it with careful planning:

*'Often if I try and do something complicated in the afternoon I don't do it the best way I could, so I try and do it the next morning, try and work around it.'*

Others distracted themselves from feelings of tiredness/fatigue:

*'If I do feel weary, if I get up and start doing something physical it does wake me up slightly.'*

*'I suppose it's the fact that I don't want to get tired, so if I think about something else I won't feel tired.'*

One person described gradually doing more and more of an aerobics tape until she could do it all in one go. Another person talked about simply pushing himself onwards in the face of fatigue.

3.4.3 Trying too hard

Despite having strategies in place, four people talked about pushing themselves too much, sometimes only realizing when it was too late:

*'It's one of my goals at the moment to ignore being tired, so I do anything to try and stretch the limits of concentration and alertness.'*

*'I have been guilty many times of trying too hard or ignoring these symptoms, of carrying on or getting involved in doing things and either making a mess of it or upsetting other people or whatever.'*



#### 3.4.4 Vicious circle of fatigue and activity

Two of those people who commented on trying too hard, also talked about a vicious circle of making the most of the limited times when they felt alert, only to feel more fatigued afterwards.

*'I've always found that I go in bouts of doing things, so I'll come out of a bad session and I'll start to feel 100 per cent and when you feel like that you'll do more.....And that's how I start to spiral down because I won't slow down. Because feeling 100 per cent is terrific for anyone, but that's how it starts and once you start to overdo it again, you're wearing out.'*

*'I need a good 10 hour sleep most of the time. That's probably because I've been pushing myself, cos I always push myself.'*

#### 3.4.5 Lack of motivation/low mood/avoidance

Lack of motivation in brain injured people can be associated with the area of the brain which has been damaged (Stuss, Gow & Hetherington, 1992). Unfortunately investigation into this area was beyond the scope of this study. Lack of motivation in the people in this group may also have been associated with depressed mood, as already reported briefly in section 3.3.3 (medication). However, it seems relevant to comment further on how fatigue and an apparent need for sleep was used by three people to avoid undesirable situations.

*'I try to stay in bed all day. If anything, it's more of a hiding away type of thing.'*

*'If I didn't like what was going on I would go and sleep to get it off my mind really.'*

The following remark was spoken of in relation to decreased attention brought on by fatigue:

*'It's an emotional thing because if you're exchanging ideas with people you hope to feel something about it, and that doesn't happen easily. And when it does happen the emotions that arise tend to be difficult things to deal with, so I suppose in a way its like a defence mechanism.'*

Once again it is notable that not everyone who lacked motivation was depressed or fatigued.

*'Well I don't really get that tired, because I don't do that much. I think lack of motivation would be a more apt description.'*

*'Normally I just sit around all day long. I mean I could quite happily sit here till the early hours of the morning.'*

**3.4.6 Change in quality of fatigue**

Four people commented on specific change in quality of fatigue following their injury. Table 13 summarises the changes noted.

**Table 13 Changes in experience of fatigue following brain injury**

Change in experience of fatigue/tiredness	Number of people
Less predictable/under conscious control	3
More mental less physical	1
More depressing	1

Respondents commented on the fact that fatigue was unpredictable, and less under conscious control:

*'Previously it was directly associated with staying up late, doing something energetic, having a long day. It felt more natural.....But now tiredness is very much less under my conscious control...'*

*'You're not happy with it because it could happen at any time of day.'*

One person linked lack of control of fatigue with depression:

*'Yes there's more a sense of depression, of hopelessness about it because there is no way of controlling it.'*

Another person commented that now that he had recovered from his injury he was tired when he expected to be, for example, when he came in from work. While he was recovering from the injury he felt that in retrospect he had been tired because he was lazy.

One person commented on changed properties of fatigue:

*'Before my injury I only really got physically tired. I never really suffered mental tiredness at all. But since the head injury I suffer mental tiredness now rather than physical tiredness.'*

### 3.4.7 Inter-linked problems

Another theme related to the presence of inter-linked problems. These are difficult to present in a table because they overlap. Categories concerning these included having limited activities, being in pain or recuperating, and mood.

Thus, some people struggled with understanding whether their fatigue was due to their brain injury or to the situation that their injury had indirectly led to:

*'I don't want to get up and there's not a discipline to enforce me to do so, so I struggle against giving up basically.'*

*'I get back to the subject of just sitting about. How much is due to that, because you can't do things as usual, and how much is to do with the problem, you know. It's a job to say really. Because forced (to rest) how much is to do with physical movement and how much to do with the head side of things.'*

*'If I'm out and about it doesn't happen. It's only if I'm sitting here. It's possibly linked to not having many things to do.'*

With regard to mood, one person commented:

*'I know that my mood gets worse as I get tired. But I couldn't say for certain which one leads to the other.'*

Another participant described fatigue in terms of lack of motivation and felt that fatigue and depression together impacted on him. Describing fatigue, he said:

*'You lose the desire, the will, the desire to do something, and it doesn't mean as much as it did before.'*

One participant commented:

*'..I'm tired and that makes me anxious, and then I can't do anything.'*

The same person also stated:

*'Anxiety sometimes leads to tiredness and fatigue'*

Others seemed clearer either about a cyclical or linear pattern. For example one person commented that worrying about being able to cope and get through the next

day sometimes made him lose sleep at night, which then led to fatigue and further anxiety. Another respondent said:

*‘I felt tired because of the pain and then that put me in a bad mood.’*

### 3.5 QUALITATIVE ANALYSIS OF DEBRIEFING QUESTION

Table 14 shows people’s feelings about having been involved.

**Table 14 Feelings about having taken part in the study**

Feeling about participation in study	Number of people
No problem/fine	16
Good to be able to talk about it	4
Good if it’s going to help others	3
Interesting to learn more about/reflect on injury	2
Good if it helps you (researcher) out	1

Nobody showed any distress at having taken part in the interview. Some people found it refreshing to be able to talk about their difficulties:

*‘It is wonderfully healing to talk about it actually.’*

*‘To bring it out into the open is always helpful.’*

Two people were keen to learn more about their injury:

*‘It’s good - any understanding I can gain is great.’*

*‘It’s interesting to actually think through the time since the accident.’*

Others hoped that their participation might help others in similar situations to themselves in the future:

*‘I would like to be able to give information that would help someone else in my situation as well’*



One theme to come from some of the longer answers to this question was the suggestion of a lack, or a concern about a lack, of services for brain injured people. Thus, some people seemed to welcome an opportunity to talk through difficulties that they had not had the chance to do elsewhere. Others' concerns focused on trying to make it easier for brain injured people in the future than it had been for themselves.

### 3.6 SUMMARY OF QUALITATIVE ANALYSIS OF RELATIVES' VIEWS

Because of restricted space it is not possible to report in the same depth the themes that emerged from interviews with relatives. In many instances themes already identified in the interviews with those who had sustained a brain injury were identified again in the relatives' interviews. The findings reported below are limited to those that show discrepancies between the two groups.

#### 3.6.1 Lack of awareness of fatigue

Relatives commented to a greater extent on the fact that their brain injured relative was not always aware of fatigue building up, and that they might need this pointed out.

*'I mean, I know, obviously when he's getting mentally tired more than he does. Because he doesn't recognise it in himself until he is really tired.'*

*'He'll say that he's not tired, but I'll think yes, that if he's a little bit snappy, then I think yes he's tired. He might not agree with me, but....'*

*'And I think what is interesting in Tom's case, although he is getting better is that he sometimes doesn't realize that he is getting very tired. That's when we have to say to him either "calm down" or "have you managed to have a sleep yet?", or "stop getting so ratty!"'*

#### 3.6.2 Daytime sleep

Another noticeable discrepancy in the information given, concerned how much the person with the brain injury slept during the day. In six instances the relative of the

brain injured person felt that they slept for longer during the day than the brain injured person felt they did.

### 3.6.3 Signs of fatigue

This factor did vary between groups to some extent, as brain injured people described sensations and relatives described visible signs. Seven people in total commented that their relatives' eyes looked different. Descriptions included 'sunken', 'bloodshot' 'black around the eyes' and 'eyes seem to bulge out of his head'.

One notable difference with regard to physical fatigue was that three people commented on the change in their relative's skin tone when they became tired.

*'Sometimes he will come in and he will be absolutely like a ghost, just totally white with sunken eyes.'*

Four people commented on gait. For example, one person was aware that their relative dragged his feet when he was tired, another that his partner's feet seemed to 'flap' more when she was tired. One relative commented:

*'When he's tired he walks round like an old man. It's an effort to get up and he stoops.'*

One sign noted by relatives only, was a tendency to lose the thread of a conversation when fatigued. Four people mentioned this.

*'And when we're all talking he loses concentration on what people are saying and then he picks up a word that you've said and he'll suddenly start talking about that. Everyone's thinking "why's he suddenly started....." It's as if he's lost it for a little bit and then comes back into the conversation.'*

### 3.6.4 Sudden fatigue

Three people commented that their relative's fatigue had changed in that it would suddenly come upon them. They described it in the following ways:

*'Yeah, if you're talking to him or if he's sitting there watching the television. He's seems to be fine one minute and the next he's absolutely fast asleep.'*

*'He reminds me of a child, he can be out and about and very active, then suddenly he's fast asleep.'*

3.6.5 Reasons for fatigue

Although all those who felt that their brain injured relative struggled with fatigue, attributed this to the brain injury, it was notable that some people blamed other factors in addition. These are shown in Table 15.

Table 15 Possible reasons for fatigue in addition to brain injury

Additional reason for fatigue/tiredness	Number of people
Medication	3
Age	2
Expectation	2
Avoidance	2

Three people wondered if the medication that their relative was on, was affecting fatigue:

*'I don't know if the medicine is affecting her. Obviously it's doing a very important job. But it may be slowing her down.'*

*'I also think it (i.e., fatigue) might be the side effects of the antidepressants.'*

Two relatives seemed to question whether fatigue was due solely to the brain injury or whether it was also influenced by age.

*'I think our ages come into it now, neither of us is getting any younger. Prior to the accident, we always seemed very young for our age. There's no doubt as you get older you slow down physically anyway. I'm convinced that...at the time of the accident something happened to me as well because it's all stopped. Everything focuses on Jane. I feel like a bit of my brain fell off as well. I can't see it improving because of our ages. I mean you get natural deterioration anyway, question is how fast!'*

*'Well I just think it's (i.e., fatigue) a natural thing by and large, and I think as you get older it occurs more often.'*

Two people commented on their partners' expectation of fatigue:

*'I think he likes to think he's tired when he's not sometimes.'*

*'I think sometimes with head injury if you're told that something will happen, you thinks it's gospel, even if it's a might be.'*

Two relatives also felt that fatigue was used to avoid situations sometimes:

*'I think it's a cop out as well. If he doesn't want to do anything that's too taxing, that he finds difficult, its always because he's tired, so I think its become a bit of an excuse sometimes.'*

*'We can never make up our minds whether it is tiredness or whether he just wants to hide away.'*

### 3.6.6 Hypotheses about fatigue

One participant in particular made some interesting hypotheses. Firstly this person wondered whether following a brain injury the type of sleep one experienced (for example, REM, non-REM) changed and had implications for sleep quality. The same respondent also commented on the personality change frequently talked about following brain injury. This person's opinion was:

*'...that this could all be down to a pervading tiredness.'*



## **PART FOUR: DISCUSSION**

## 4.0 DISCUSSION

### 4.1 DISCUSSION OF RESEARCH FINDINGS

#### 4.1.1 Brain injury and fatigue

Subjective experience of fatigue was found not to be associated with severity of brain injury. This is in accordance with previous findings (McKinlay, Brooks, Bond, Martinage & Marshall 1983; Oddy *et al.*, 1978) suggesting that the experience of fatigue is not related directly to brain damage.

It is notable that there was a high correlation between brain injury related symptoms identified by brain injured participants and subjective view of fatigue. Thus, those who identified more problems generally were also more likely to identify fatigue as a problem. Scores on the brain injured participants' checklists did not correlate significantly with duration of PTA. This suggested that not only fatigue, but various other sources of distress experienced by brain injured individuals, were not directly related to severity of injury as measured by PTA.

The moderate correlation between brain injured participants' experience and relatives' impressions of degree of symptoms, suggests that relatives had a certain level of understanding of what their brain injured relative was experiencing. This was also in accordance with most relatives' descriptions at interview of the fatigue that they were aware of in their brain injured relative. Additionally, the fact that there was no significant correlation between relatives' scores on this measure and length of PTA further stresses the difference between severity of injury and experience of problems

that follow. However, while the symptom checklist scores of those with a brain injury correlated with their subjective level of fatigue, relatives' impressions of symptoms did not correlate with brain injured people's experience of fatigue. This emphasises the different perspectives of brain injured people and their relatives in some cases, and is reflected in the moderate level of correlation between checklist scores. This finding may have been affected by the opinion of a small minority, which was evident at interview. Three people wondered if their brain injured relative sometimes used their injury or fatigue as an excuse to avoid undesired activities, or felt that their fatigue was more of a problem than it actually was. Although the majority of people's opinions of their brain injured relatives' experience of fatigue seemed very close to the individuals' subjective views, it is possible that where these views differed there was added stress in the household. Given that stress was identified by some people as inducing fatigue, one might hypothesise that added stress in a minority of households brought on by different views of fatigue, might exacerbate the experience of fatigue for the brain injured person.

Theories of reduced information processing capacity are perhaps the most influential to date in offering explanations for fatigue following brain injury. It is notable that a number of participants commented specifically on reduced information processing capacity. Others did not make specific reference to this term but described instances where they struggled because they could 'never focus on more than one thing at once', or that when they were fatigued, trying to do more than one thing got them 'into a real state'. Some people mentioned increased mental slowness when describing tasks that they would have done before with little effort. One person

commented for example, that it took him longer to do his accounts, and he felt more tired when he had finished them.

In relation to brain injury, information processing theory suggests that tasks become more effortful due to the damage incurred by the injury. This might imply that they take longer to achieve and/or that the person feels more fatigued by completion. This was clearly a relevant issue in the day to day struggles described by some participants. However, interestingly, performance on the speed of information processing task showed no correlation with reported level of subjective fatigue. Thus, despite fatigue being a significant disability for some members of the sample, they were nevertheless able to perform at a similar level to those who did not profess to suffer with undue fatigue. This finding bears resemblance to research on chronic fatigue that shows that perceptions of reduced capabilities do not always match performance, and to sleep studies that report a discrepancy between actual alertness and feelings of sleepiness following oversleep. The information processing task used in the current study was very brief and this has to be considered when making any inferences about this finding. However, rather than supporting an information processing theory, it suggests that fatigue following brain injury may be less related to performance impaired by brain damage and more with other factors.

These findings stress the complexity of the phenomenon under discussion. The implication is that following a brain injury, other factors come into play that affect an individual's sense of wellbeing and how fatigued they feel. These factors are not related directly to the severity of the brain injury, or to the ability of an individual to perform a particular task. Instead they may relate to physical injuries incurred at the



same time, or to lifestyle and/or mood changes that follow the injury. The introduction stressed the multi-dimensional nature of fatigue and this was evident in the present study. The rest of the discussion considers the results with this multi-dimensional nature of fatigue in mind.

#### **4.1.2 Sleep and fatigue**

Fatigue and tiredness are often associated with lack of sleep, indeed the definition of tiredness includes a 'readiness for sleep' (The Concise Oxford Dictionary, 1991). The average amount of sleep a night is 7.5-8 hours (Horne, 1991). Apart from two participants who slept for less than six hours a night, everyone slept at least seven hours a night. Three-quarters of the sample slept between eight and 11 hours a night. Given that 10 people also slept during the day, it seems fair to comment that this group on average had more sleep over a 24 hour period than many people do. Additionally, relatives either agreed with the brain injured participants' estimate of their hours of sleep or said that it was higher: no relatives said that it was lower. Thus, at first glance there appears to be a discrepancy between the fact that many people slept a lot yet remained fatigued.

There are several possible explanations for the elevated amount of sleep. Firstly, as some people pointed out, sleep was not always refreshing. While some participants described their sleep quality as very good, others commented that it was variable or poor. One hypothesis from a relative concerned the possibility that brain injury might result in missed or reduced restorative stages of sleep, which is similar to Horne's (1991) assertion that core sleep (the first 3-4 cycles) is of greater importance in restoring function to the cerebrum than optional sleep. Secondly, sleep serves a

restorative function (Horne, 1991) and may well have been part of the continued natural healing process for some people following their injury. Given Horne's finding that core sleep is particularly important to the cerebrum, it might be hypothesised that people with frontal lobe damage might need more sleep for recuperation following wakefulness. Thirdly, hours of sleep may have reflected a less structured lifestyle following injury, where more unstructured time allowed for more sleep, or where low mood, lack of motivation or boredom caused people to sleep for longer. As noted in the introduction, various studies have investigated 'worn out' syndrome, a state of fatigue brought on by extended sleep, which may have been a factor for some participants. - Thus, it appears that for physiological or psychological reasons, or possibly both, many people in this study lacked the commonly accepted cause-effect relationship between an optimal amount of sleep and restored vitality.

#### **4.1.3 Working, not working and fatigue**

Another factor to be considered when taking into account individuals' subjective experiences of fatigue is daytime activity. One person at least drew attention to this. He commented that although he did not regard fatigue as a problem, his lifestyle was such that he could sleep whenever he wished because of no competing commitments. This participant lived alone and did not work. Others commented that they felt most tired at the end of a day's work or at the end of their working week. Thus, it is possible that those for whom the repercussions of their injuries were too severe to allow them to work, may have been less fatigued because they could organise their lives in a non-demanding way. Those who had been less severely affected by their injuries had returned to work but became fatigued by trying to live up to their pre-injury performances. If this were the case it might explain the lack of correlation in

this study between subjective experience of fatigue severity and severity of brain damage as measured by PTA. It is also possible that the nature of an individual's job will have affected how likely they were to be able to return to work, and the degree to which it was going to tire them. One person in the sample had begun working again full time, but had given up. He explained that he was 'shattered' and that much as he liked his job and had been 'working up to it for years', it was too complicated and stressful. As he struggled to continue his job, this participant became depressed and was signed off sick. This interplay between fatigue and mood is an important dynamic which will be discussed further below.

The idea that the relationship between severity of brain injury and subjective experience of fatigue is affected by how much a person is able to do, is an interesting possibility. However, in this study many people commented on inactivity leading to fatigue, which was often associated with boredom. Thus, one might argue that while an individual who is able to work may grow tired from industry, an individual who is unable to work may grow tired from lack of industry and lack of stimulation. Unfortunately, the complexity of this issue grows because of the uncertain role of motivation. Some of those who found that 'sitting around' led to fatigue made a conscious effort to combat it by doing something active. One person who did not see fatigue as a problem differentiated between fatigue and motivation, and recognised that he had little of the latter and therefore spent much of his day in inactivity. Motivation or lack of it may have links with depression. Clearly one of the findings of this study, in keeping with the literature on fatigue, is that it is a symptom of many problems and that this presents difficulties if one is trying to understand its relationship to one particular variable. It is also clear that subjective experiences of

two people who were less motivated questioned the effectiveness of medication and wondered if it was slowing their relatives down.

The other mood state frequently commented upon, was irritability and losing one's temper more often than prior to the injury. Many people linked loss of temper with feeling fatigued (although it should be noted that irritability can also be a feature of major depression [DSM IV, APA, 1995]). It could be argued that losing one's temper might be aligned to a reduced ability to cope with a situation. Indeed, reduced ability to cope was given as part of the definition of fatigue by some participants. Additionally, losing one's temper is a form of losing control and this was a theme that emerged from some people when they described their fatigue.

Some participants noted that mood and/or motivation were inter-linked with fatigue, and acknowledged that it was difficult to know which factor had led to what end, or whether they were related in a circular dynamic. Clearly, it would be very difficult to determine the direction of an association between fatigue and elements of mood. It is perhaps more useful simply to note the involvement of a number of factors such as mood state, coping level, motivation level, and degree of feeling in control. As well as interacting with each other, these factors interact with subjective feelings of fatigue, and may be manifested overall by a feeling of fatigue in the brain injured person. Given the different factors that might be involved, it is possible that some people in the study shared similar experiences of a mixture of symptoms, but that some labelled these 'fatigue' and others labelled them differently, for example, feeling 'low' or 'stressed' or 'not in control'.



#### **4.1.5 Awareness of fatigue**

One factor relating to mood that was raised more frequently by relatives than those who had been brain injured, was a lack of awareness of the onset of fatigue. A number of people commented on the need to suggest to their brain injured relative that they have a rest or a sleep. The sign evident to relatives in these situations was most often a deterioration in temper, although some also commented on a realization that the brain injured person was no longer following a conversation. One brain injured participant stated that at times his lack of awareness of his level of fatigue had got him into uncomfortable situations that he was not able to handle due to reduced capability brought on by fatigue. A few brain injured participants were thus aware that their behaviour changed when they were fatigued and for some this was a source of anxiety because they knew that they lacked awareness of the onset of fatigue and the change in behaviour that followed.

#### **4.1.6 Reduced energy**

One argument about fatigue experienced following brain injury is that it is due to the continued compensational effort required in meeting the demands of a 'normal' life (van Zomeren, Brouwer & Deelman, 1984). This was certainly a theme that emerged from the current study. A number of participants commented on how exhausted they felt just trying to get through a day, or in 'having fun'. In some instances a sense was conveyed of having forgotten how tiring everyday life was, for example the comment quoted earlier: 'I am just amazed at the amount of energy one needs to conduct a normal day.'

The theme of reduced energy was often referred to at the same time as difficulties in getting through the day. Some people in the study tired more easily than prior to their injury, and it is unclear whether this was because more effort was required to perform an activity or because there was less energy available with which to carry out the task. Whichever reason, one consequence of this was greater time needed for recuperation. This was one factor that led to difficulties in deciding in the study whether fatigue was a problem or not for some people. While some people were clear that this was a very negative consequence of their injury, that prevented them from doing or enjoying many of the things they had prior to their injury, others gave more complex responses. One person commented for example, that fatigue did not stop him doing anything, but that post injury, he could accomplish less in a day. Thus, while still able to carry out all their activities, for some people this was in a limited capacity.

Most participants did not describe their fatigue in such totally debilitating terms as chronic fatigue sufferers seem to (Schweitzer *et al.*, 1995; Anderson & Ferrans, 1997). Nevertheless, there are notable similarities, for example having to take frequent rests, or pace oneself through the day, or suddenly realizing that there is insufficient energy left to complete a particular task or activity.

One other interesting theme concerning fatigue which seemed to be related to levels of energy was that people found it unpredictable. Some participants commented that apart from occurring more frequently than it had done prior to their injuries, there was not necessarily a pattern to when fatigue appeared. Thus, the unpredictability for

some, of when the energy would run out, was another way in which fatigue was out of people's control.

## **4.2 METHODOLOGICAL CONSIDERATIONS**

### **4.2.1 Mixed methodology**

The qualitative approach taken was considered suitable to the subjective nature of the phenomenon under study. Given the multidimensional nature of fatigue, the quantitative measures were also useful though, in providing some general associations between variables, for further consideration. However, quantitative results need to be considered with the small sample size in mind and the issues this raises concerning statistical power, although some of the high levels of significance obtained reduce this concern somewhat. Thus the two approaches were considered to complement each other by providing information on the subjective experience of fatigue, and some significant associations between fatigue and other variables.

### **4.2.2 Recruitment**

Because only 22 of 62 people contacted responded, it is uncertain whether they constituted a representative sample. Various reasons may account for people not responding. They may have had less interest in the study, less desire to assist in finding out about fatigue following brain injury, less time to give. They may have had anxieties about what was involved: would they be able to verbalise their feelings; would an interview allow unpleasant memories to resurface; would their answers reveal something 'wrong' about them to the researcher? Further possibilities for not responding may have related to some of the difficulties experienced following brain injury: memory impairment or lack of motivation may have inhibited responses. It is

also possible that some people felt too fatigued to respond or to cope with an interview and completion of questionnaires. Alternatively, one might further hypothesise that those for whom fatigue was a problem would be more eager to participate in a study that focused on a difficulty that affected them personally.

Many more men than women responded which made it difficult to consider the role of gender in relation to fatigue. Although a shortcoming of the study, it is one that might prove difficult to address in future research because of the overrepresentation of males generally in brain injury.

#### **4.2.3 Interviews**

Interviews were conducted at various times of day to fit in with the commitments of participants. Fatigue level at the time of interview could have influenced responses both generally, and more specifically on the speed of information processing task. However, it would have been impossible to conduct all interviews at exactly the same time of day for practical reasons. Had this been possible, problems would still have arisen from the fact that individuals felt most alert at different times of day.

The speed of information processing task followed immediately on from the interviews, which were of varying length, depending on how much individuals had to say. It is possible that the level of fatigue resulting from being interviewed varied between individuals, and that this may have affected performance on the information processing task. One way that this could have been avoided would have been to have given the task before the interview. This has two drawbacks. Firstly, it is not known what people may have been doing prior to this that may have fatigued them.



Secondly, the administration of the information processing task immediately upon arrival would not have been conducive to putting participants at their ease and building rapport.

Significant correlations between measures of fatigue produced evidence of concurrent validity of these measures. It may have been interesting to ask people to complete the fatigue questionnaires at different times of day however, to see if this affected responses. Although the WSRS is validated and is designed for people with neurological problems, it does not differentiate between different mood states. This meant that only a general measure of mood was attained. This problem was reduced by provision of more detailed information during interview that complemented the statistics.

#### **4.2.4 Omissions**

Little attention was paid to the role of physical injuries, although a number of participants had sustained these to varying degrees, with varying lengths of time for recovery. It is reassuring to note, however, that some of those who had sustained the most debilitating or multiple physical injuries still spoke about fatigue chiefly in terms of mental process.

Although relatives' views of their brain injured relatives' fatigue were canvassed through interview, they were not asked to complete any quantitative measures of their impression of their relatives' fatigue level. Initially, it was considered that this was not important as it was the brain injured person's opinion that was essential.

However, with hindsight, this additional data would have been useful in making inferences about subjective experience and objective impressions of fatigue.

It is possible that the medication some people were on could have induced feelings of fatigue, and for this reason it may have been better to exclude them. Because such effects are a possibility rather than a certainty and because subjective experience was valued in this research, this was not done. However, because of this decision, medication needs to be recognised as a further variable that may affect the experience of fatigue following brain injury.

#### **4.2.5 Final comments on methodology**

Results relating to the information processing task need to be treated with caution. As already mentioned, this test was very brief. Also, people may have tried extra hard under 'test conditions'. Although this task had been used in previous work with brain injured people by the research supervisor, test-re-test reliability could have been assessed in the current study. The possibility of low statistical power, that is, that the test used was too error-prone to correctly reject a false null hypothesis, must not be overlooked. Power would also have been increased by a larger sample size. The quantitative results on information processing need to be balanced against qualitative comments pertaining to information processing, which were frequent, even though no direct questions were asked about this. The open nature of most questions on the interview schedule suited the approach used, although some questions might have been more appropriately placed in the initial structured questionnaire.

### **4.3 CLINICAL IMPLICATIONS**

This study has highlighted the distress that can be brought about by fatigue following brain injury. If fatigue is not ruled out as an inevitable physiological consequence of brain injury, there may be more motivation amongst service providers to address the problem.

#### **4.3.1 Education**

Given the eagerness of some respondents to learn more about their own or their relative's condition, it seems that increased understanding may assist people to cope with change following brain injury. Greater awareness that individual perceptions of the brain injured person's fatigue are likely to differ slightly would be useful. One of the findings of this study is that some people can still do all the things they did prior to their injury, but the amount they can do in one day is less. Increased awareness of this possibility might help individuals to make realistic plans for each day.

#### **4.3.2 Practical help**

Approaches would depend on the presenting problems of the individual, but many might focus on coping strategies. For those whose fatigue appears to result from trying too hard, an approach that paces activity would be appropriate. Unmotivated people, or those linking their fatigue with boredom, might benefit from a daily activity programme. Relatives could be involved in encouraging adherence to such a programme. Given the amount that some participants slept, and in view of the 'worn out' syndrome, interventions focusing on sleep hygiene might be useful. This study reported a lack of awareness of fatigue, and it was described by some as unpredictable. Relatives could take a role in increasing awareness. Additionally,

individual work might aim to identify antecedents that trigger fatigue, in this way possibly decreasing temper outbursts, and increasing personal control. Another approach would be for therapeutic approaches to focus on depression or anxiety and for fatigue to be tackled indirectly through these difficulties.

On a larger scale, job placement schemes sensitive to the difficulties brought on by fatigue and other factors following brain injury, might help to fill a gap in service provision that was made clear during the course of the study.

#### **4.3.3 Emotional support**

The suffering described by some people in this study emphasises the need for emotional support from services. This might take the form of individual or family work, or support groups both for brain injured people and for their relatives.

### **4.4 FUTURE RESEARCH**

Although this study was informative because no previous studies have focused qualitatively on fatigue in brain injured people, it was very small. Repetition on a larger scale with the improvements discussed in section 4.2 might be useful in further investigating how people use and understand the term fatigue. This study relied on brain injured participants being able to consider current experiences of fatigue in relation to pre-injury experiences. However, it might be advantageous to conduct a study comparing brain injured people with non brain injured controls.



Researchers might pursue a greater understanding of fatigue by investigating the experience of different clinical groups, for example, individuals with chronic fatigue, or physical disability. Subjective experience might then be compared and contrasted with the experiences of brain injured people.

Additionally, research could focus on particular aspects of fatigue in relation to brain injury. For example, a study comparing a group of fatigued, depressed, brain injured people with fatigued, non-depressed, brain injured people, would control for low mood and assist understanding of the impact of brain injury on fatigue. A similar study might involve anxiety instead of depression. Research involving a more narrow band of people with regard to severity of injury, might be useful in considering how fatigue may affect return to work and how this in turn may affect extent or nature of fatigue experienced. Related to this, research focusing on lifestyle and type of job prior to injury might inform understanding of different experiences of fatigue and expectations following injury. The relationship between information processing and subjective fatigue also needs more attention. Studies addressing this might adopt an experimental approach, for example, a specific task followed by a speed of information processing test, and a verbal report of subjective fatigue. The key to research in this area, even though a study may be focusing on one specific aspect of it, is continued awareness of the multi-dimensional nature of fatigue.

#### 4.5 CONCLUSION

A number of specific difficulties were found in the way people experience fatigue following brain injury. This included a reported depletion in energy levels. While

some were aware of this and rationed their activities accordingly, others described suddenly running out of energy and needing to stop what they were doing abruptly. The onset of fatigue at unexpected times was linked by some respondents to an unpleasant feeling of not being in control. In connection with this, it was commented that there was generally less awareness of the onset of fatigue and that the warning sign to relatives was more often than not irritability and loss of temper.

Although some people talked about not being able to concentrate on more than one thing at once, and of being slowed down, information processing speed was not found to be associated with subjective reports of fatigue severity. This study does not therefore support the idea that fatigue following brain injury is due solely to reduced information processing ability. Coupled with the finding that duration of PTA was also not associated with subjective ratings of fatigue severity, it seems that factors other than the extent of brain damage influence the subjective experience of fatigue.

There seem to be two possible conclusions from this. Either it is possible that people in the sample were fatigued for different reasons, all of which may have resulted from the brain injury. For example, fatigue may have been linked to depression, or anxiety, or poor sleep, or coping with return to work, or specific physiological brain damage. Alternatively, it could be argued that the combined effects of a brain injury such as those just described, may produce a certain feeling that some people describe as fatigue. The degree of fatigue experienced is likely to relate partially to the brain injury directly, but will also be influenced by psychological and emotional factors, such as expectations and lifestyle prior to the injury.

## 5.0 REFERENCES

- Akerstedt, T. (1991). Sleepiness at work: effects of irregular work hours. In T.H. Monk (Ed), Sleep, Sleepiness and Performance, pp. 129-152. Chichester: Wiley.
- Anderson, J.S. & Ferrans, C.E. (1997). The quality of life of persons with chronic fatigue syndrome. The Journal of Nervous and Mental Disease, 185, 6, 359-367.
- Barmack, J.E. (1937). Boredom and other factors in the physiology of mental effort: an exploratory study. Archives of Psychology, 218, 1-83.
- Bartley, S.H. & Chute, E. (1947). Fatigue and Impairment in Man. New York: McGraw-Hill.
- British National Formulary. (1999). London: British Medical Association and British Pharmacological Society of Great Britain.
- Brown, I. (1994). Driver fatigue. Human Factors, 36, (2) 298-314.
- Buchwald, A. & Rudick-Davis, D. (1993). The symptoms of major depression. Journal of Abnormal Psychology, 102, 197-205.
- Buchwald, A., Sullivan, J., & Komaroff, A. (1987). Frequency of chronic-active epstein- Barr virus infection in a general medical practice. Journal of American Medical Association, 257, 2303-2307.
- Burton, L.A. & Volpe, B.T. (1994). Depression after head injury: do physical and cognitive sequelae have similar impact? Journal of Neurological Rehabilitation, 8, 63-67.
- Cameron, C. (1973). A theory of fatigue. Ergonomics, 16, (5) 633-648.
- Carskadon, M.A., Mancuso, J., Keenan, S., Littell, W. & Diment, W.C. (1986). Sleepiness following oversleeping. Sleep Research, 15, 70.
- Chalder, T., Berelowitz, G., Pawlikowska, T., Watts, L., Wessely, S., Wright, D. & Wallace, E.P. (1993). Development of a fatigue scale. Journal of Psychosomatic Research, 37, 2, 147-153.
- Christensen, L., & Duncan, K. (1995). Distinguishing depressed from nondepressed individuals using energy and psychosocial variables. Journal of Consulting and Clinical Psychology, 63, 495-498.
- Cobb, I. (1920). A Manual of Neurasthenia (Nervous Exhaustion). London, Balliere, Tyndall and Cox. Cited in Wessely, S, Hotopf, M. & Sharpe, M. (1998). Chronic Fatigue and its Syndromes. New York: Oxford University Press.

Concise Oxford Dictionary, The. (1991). English Ed. St Ives: Oxford University Press.

Coughlan, A.K. & Hollows, S.C. (1985). The Adult Memory and Information Processing Test. Available from A.K. Coughlan, St James University Hospital, Beckett Street, Leeds.

Coughlan, A.K. & Storey, P. (1988). The Wimbledon Self Report Scale: emotional and mood appraisal. Clinical Rehabilitation, 2, 207-213.

Davies, D.R., Shackleton, V.J., & Parasuraman, R. (1983). Monotony and Boredom. In G.R.J. Hockey (Ed), Stress and Fatigue in Human Performance, pp. 1-32. Chichester: Wiley.

Diagnostic and Statistical Manual of Mental Disorders, 4<sup>th</sup> Ed. (1995). Washington, DC: American Psychiatric Association.

Fenichel, O. (1934). On the psychology of boredom. Imago, 20, 270-281. Cited in Davies, D.R., Shackleton, V.J., & Parasuraman, R. (1983). Monotony and Boredom. In G.R.J. Hockey (Ed), Stress and Fatigue in Human Performance, pp. 1-32. Chichester: Wiley.

Finkelman, J.M. (1994). A large database study of the factors associated with work induced fatigue. Human Factors, 36, (2) 232-243.

Glaser, B. & Strauss, A. (1967). The Discovery of Grounded Theory: Strategies for Qualitative Research. York: Aldine.

Glaus, A. Crow, R. & Hammond, S. (1996). A qualitative study to explore the concept of fatigue/tiredness in cancer patients and in healthy individuals. European Journal of Cancer Care, 5, suppl.2, 8-23.

Globus, G.G. (1969). A syndrome associated with sleeping late. Psychosomatic Medicine, 31, 528-535.

Grandjean, E. (1979). Fatigue in industry. British Journal of Industrial Medicine, 36, 175-186.

Hartmann, B.O. (1967). Psychological factors in flying. International Psychiatry Clinics, 4 (1) 185-196.

Henwood, K. & Pidgeon, N. (1995). Grounded theory and psychological research. The Psychologist, 8, (3) 115-118.

Herscovitch, J., Stuss, D. & Boughton, R. (1980). Changes in cognitive processing following short-term cumulative partial sleep deprivation and recovery oversleeping. Journal of Clinical Neuropsychology, 2, 301-319.



Hillier, S., Sharpe, M.H. & Metzger, J. (1997). Outcomes five years post-traumatic brain injury (with further reference to neurophysical impairment and disability). Brain Injury, 11, (9) 661-675.

Hinkleday, N.S. & Corrigan, J.D. (1990). The structure of head injured patients' neurobehavioural complaints: a preliminary study. Brain Injury, 4, 115-133.

Horne, J.A. (1988). Sleep loss and divergent thinking ability. Sleep, 11, 528-536.

Horne, J.A., (1991). Dimensions to sleepiness. In T.H. Monk (Ed), Sleep, Sleepiness and Performance, pp. 169-196. Chichester: Wiley.

Jorge, R.E., Robinson, R.G. & Starkstein, S.E. (1993). Comparison between acute and delayed onset depression following traumatic brain injury. Journal of Neuropsychiatry and Clinical Neurosciences, 5, 43-49.

Kant, R., Duffy, J.D., & Pivovarnik, A. (1998). Prevalence of apathy following head injury. Brain Injury, 12, (1) 87-92.

Kubose, S.K. (1972). Motivational effects of boredom on children's response speeds. Developmental Psychology, 6, 302-305.

Masson, F., Maurette, P., Salmi, L.R., Dartigues, J.F., Vecsey, J., Destailats, J.M. & Erny, P. (1996). Prevalence of impairments five years after head injury, and their relationship with disabilities and outcome. Brain Injury, 7, 487-497.

McKinlay, W.W., Brooks, D.N., Bond, M.R., Martinage, D.P. & Marshall, M.M. (1983). Postconcussional symptoms, financial compensation and outcome of severe head injury. Journal of Neurology, Neurosurgery and Psychiatry, 6, 1084-1097.

Meltzer, H., Gill, D., Petticrew, M, & Hinds, K. (1995). The Prevalence of Psychiatric Morbidity Amongst Adults Living in Private Households. London: HMSO.

Miller, E. (1970). Simple and choice reaction time following severe head injury. Cortex, 6, 121-127.

Mosso, A. (1904). Fatigue. Swan Sonnenschein and Co. Cited in Wessely, S., Hotopf, M. & Sharpe, M. (1998). Chronic Fatigue and its Syndromes. New York: Oxford University Press.

Montgomery, G. (1983). Uncommon tiredness among college undergraduates. Journal of Consulting and Clinical Psychology, 51, 517-525.

Montgomery, G.K. (1995). A multi-factor account of disability after brain injury: implications for neuropsychological counselling. Brain Injury, 9, (5) 453-469.

Muscio, B. (1921). Is a fatigue test possible? British Journal of Psychology, 12, 31-46.

Neville, K.J., Bisson, R.U., French, J., Boll, P.A., & Storm, W.F. (1994). Subjective fatigue of C-141 aircrews during operation desert storm. Human Factors, 36, (2) 339-349.

Oddy, M., Coughlan, T., Tyerman, A. & Jenkins, D. (1985). Social adjustment after closed head injury: a further follow-up seven years after injury. Journal of Neurology, Neurosurgery and Psychiatry, 48, 564-568.

Oddy, M., Humphrey, M. & Uttley, D. (1978). Stresses upon the relatives of head-injured patients. British Journal of Psychiatry, 133, 507-513.

Olver, J.H., Ponsford, J.L. & Curran, C.A. (1996). Outcome following brain injury: a comparison between 2 and 5 years after injury. Brain Injury, 10, (11) 841-848.

Paley, M.J. & Tepas, D.I. (1994). Fatigue and the shiftworker: firefighters working on a rotating shift schedule. Human Factors, 36, (2) 269-284.

Pawlikowska, T., Chalder, T., Hirsch, S., Wallace, P., Wright, D., & Wessely, S. (1994). A population based study of fatigue and psychological distress. British Medical Journal, 308, 763-767.

Piper, B.F., Lindsey, A.M., Dodd, M.J., Ferketich, S., Paul, S.M. & Weller, S. (1989). The development of an instrument to measure the subjective dimension of fatigue. In S.G. Funk, E.M. Tornquist, M.T. Champagne, L.A. Copp, & R.A. Wiese (Eds), Key Aspects of Comfort: Management of Pain, Fatigue, and Nausea, pp. 199-207. New York: Springer.

Pearce, S. & Richardson, A. (1996). Fatigue in cancer: a phenomenological perspective. European Journal of Cancer Care, 5, 111-115.

Ponsford, J. (1995). Mechanisms, recovery, and sequelae of traumatic brain injury: a foundation for the REAL approach. In J. Ponsford, S. Sloan & P. Snow, (Eds), Traumatic Brain Injury: Rehabilitation For Everyday Living, pp. 1-31. Hove: Lawrence Erlbaum Associates.

Ream, E. & Richardson, A. (1996). Fatigue: a concept analysis. International Journal of Nursing Standards, 33, (5) 519-529.

Riese, H., Hoedemaeker, M., Brouwer, W.H., Mulder, L.J.M., Cremer, R. & Veldman, J.B.P. (1999). Mental fatigue after very severe closed head injury: sustained performance, mental effort, and distress and two levels of workload in a driving simulator. Neuropsychological Rehabilitation, 9, (2) 189-205.

Schmitter-Edgecombe, M. (1996). Effects of traumatic brain injury on cognitive performance: an attentional resource hypothesis in search of data. Journal of Head Trauma Rehabilitation, 11, (2) 17-30.

Schmitter-Edgecombe, M., Marks, W., Fahy, J.F. & Long, C.J. (1992). Effects of closed head injury on three stages of information processing. Journal of Clinical Experimental Neuropsychology, 14, 728-748.

Schweitzer, R., Kelly, B., Foran, A., Terry, D. & Whiting, J. (1995). Quality of life in chronic fatigue syndrome. Social Science and Medicine, 41, (10) 1367-1372.

Schwartz, J.E., Jandorf, L. & Krupp, L.B. (1993). The measurement of fatigue: a new instrument. Journal of Psychosomatic Research, 37, (7) 753-762.

Sharpe, M., Archard, L., & Banatvala, J. (1992). Chronic fatigue syndrome: guidelines for research. Journal of the Royal Society of Medicine, 152, 1604-1609.

Smith, J.A. (1995). Qualitative methods, identity and transition to motherhood. The Psychologist, 8, (3) 122-125.

Sohlberg, M.M. & Mateer, C.A. (1989). Introduction to Cognitive Rehabilitation: Theory and Practice. New York: Guilford Press.

Spikmen, J.M., Berg, I.J. & Deelman, B.G. (1995). Spared recognition capacity in elderly and closed head injury subjects with clinical memory deficits. Journal of Clinical Experimental Neuropsychology, 17, 29-34.

SPSS (INC) (1995). Statistical Package for Social Science for Windows, Version 5.0, SPSS: Chicago.

Stuss, D.T., Gow, C.A. & Hetherington, C.R. (1992). 'No longer Gage': frontal lobe dysfunction and emotional changes. Journal of Consulting and Clinical Psychology, 6, (3) 349-359.

Stuss, D.T., Stethem, L.L., Hugenholtz, H., Picton, T., Pivik, J. & Richard, M.T. (1989). Reaction time after head injury: fatigue, divided and focused attention, and consistency of performance. Journal of Neurology, Neurosurgery and Psychiatry, 52, 742-748.

van Zomeren, A.H. & Brouwer, W.H. (1987). Head injury and concepts of attention. In H.S. Levin, J. Grafman, & H.M. Eisenberg (Eds), Neurobehavioural Recovery From Head Injury, pp. 398-415. New York: Oxford University Press.

van Zomeren, A.H., Brouwer, W.H. & Deelman, B.G. (1984). Attentional deficits: the riddles of selectivity, speed and alertness. In N. Brooks (Ed), Closed Head Injury: Social and Family Consequences, pp. 74-107. Oxford: Oxford University Press.

van Zomeren, A.H. & van den Burg, W. (1985). Residual complaints of patients two years after severe head injury. Journal of Neurology, Neurosurgery and Psychiatry, 48, 21-28.

Varvaro, F., Sereika, S.M., Zullo, T.G. & Robertson, R.J. (1996). Fatigue in women with myocardial infarction. Health Care for Women International, 17, 593-602.

Wearden, A. & Appleby, L. (1997). Cognitive performance and complaints of cognitive impairment in chronic fatigue syndrome (CFS). Psychological Medicine, 117, 81-90.

Webb, H. & Parsons, L. (1991). Chronic PVFS in the neurology clinic. In R. Jenkins & J. Mowbray (Eds), Post Viral Fatigue Syndrome, pp. 233-239. Chichester: Wiley.

Wessely, S, Hotopf, M. & Sharpe, M. (1998). Chronic Fatigue and its Syndromes. New York: Oxford University Press.



## **LIST OF APPENDICES**

- Appendix 1**    **Covering introductory letter from the research supervisor**
- Appendix 2**    **Introductory letter from researcher**
- Appendix 3**    **Client information sheet**
- Appendix 4**    **Consent form**
- Appendix 5**    **Opt-in form**
- Appendix 6**    **Relatives information sheet**
- Appendix 7**    **Letter explaining time limit of study**
- Appendix 8**    **Letter of ethical approval**
- Appendix 9**    **GP letter**
- Appendix 10**   **Structured questionnaire**
- Appendix 11**   **Interview schedule - clients**
- Appendix 12**   **Interview schedule - relatives**
- Appendix 13**   **Respondent validity**
- Appendix 14**   **Inter-rater reliability stage 1**
- Appendix 15**   **Inter-rater reliability stage 2**
- Appendix 16**   **Auditability**
- Appendix 17**   **Speed of information processing task**
- Appendix 18**   **Visual analogue scales**
- Appendix 19**   **Fatigue Assessment Instrument**
- Appendix 20**   **Wimbledon Self Report Scale**
- Appendix 21**   **Symptom checklist for brain injury related symptoms (clients)**
- Appendix 22**   **Symptom checklist for brain injury related symptoms (relatives)**

## APPENDIX 1

March 31 1999

Dear

I am writing to ask for your help in a research study. The study is looking at how feelings of tiredness and fatigue may be affected by head injury. We wish to talk both to people for whom fatigue is a problem and to people for whom it is not. This is being carried out by Catharine Pedroza under my guidance.

I enclose a letter from Catharine about the study and I would be very grateful if you would agree to help. The results of the study will be anonymous and no personal details will be disclosed.

Yours sincerely

Dr Michael Oddy  
Consultant Neuropsychologist

## APPENDIX 2

March 3 1999

Dear

I am a psychologist in clinical training, working on a research project with Dr Michael Oddy at Head Injury Rehabilitation Unit. I am currently contacting people who have had links with in the past, in the hope that they will wish to participate in this research study, which investigates experiences of tiredness and fatigue following head injury. I am interested in talking both to people for whom fatigue is a problem and people for whom fatigue is not a problem.

I enclose an information sheet which gives an overview of the study and explains what would be involved if you agree to take part. Two weeks after you receive this letter I would like to make telephone contact with you to discuss the study in more detail. If you wish to participate, please return the slip enclosed in the prepaid envelope provided. We can then arrange a convenient time to meet.

Thank you for taking the time to read this letter. I hope that you will feel able to support me in conducting this research. If you have any queries, please leave a message for me with Wendy Julian, , and I will get back to you.

Yours sincerely

Catharine Pedroza  
Psychologist in Clinical Training

## APPENDIX 3

### INFORMATION ABOUT THE STUDY

#### Working title of the study

Fatigue following acquired head injury

#### About the study

We know that tiredness and fatigue are extremely common after a head injury yet they have been given very little attention in the scientific and rehabilitation literature. The study aims to find out what makes people who have had head injury tired and fatigued, and to find out more about how this affects people's lives. The study will also consider whether tiredness is associated with other factors, for example, your mood state or whether or not you are employed.

#### What participation will involve

If you agree to participate, I will visit you in your own home. Initially, I will spend time talking to you about your own experience of fatigue. With your permission, I would like to record this interview so that I have an accurate record of what you have told me. Following this, I will give you some questionnaires which I would like you to fill in. I will then ask you to complete a simple task on pen and paper lasting four minutes. Finally, I will ask you what it felt like to participate in the research. There will be time to discuss any of your feelings arising from it at this point if you wish. You will also be given the phone numbers of local support services should you wish to discuss further any issues that arise. The visit will last approximately 1 hour.

We would also very much like to talk to a close relative. *If you are happy for us to do this*, please could you pass the enclosed information pack labelled 'for the attention of a close relative' to your relative. If your relative does choose to participate, the length of the visit will be approximately 2 hours.

#### Your rights if you agree to participate

*Participation in this study is voluntary.* Refusal to participate will not affect any treatment you may currently be receiving or may receive in the future. If you agree to participate, you are free to withdraw your involvement at any stage. You are also free not to answer individual questions if you do not wish to. If you decide to take part I will ask you to sign a consent form, and I have enclosed a copy of this form so that you can see what it involves.

#### Confidentiality and results

All identifying information will be treated as anonymous. If quotes are used in the report they will be short and it will not be possible to identify them. Tape recorded interviews will be erased following completion of the project. The only people to see the written versions of the interviews will be myself and Dr Oddy, and one other psychologist, for the purposes of coding the information you give us. A summary of the findings will be sent to any participant who is interested in the outcome of the study.



CONSENT FORM

To be completed by all individuals agreeing to participate in the study.

WORKING TITLE OF STUDY: Fatigue following acquired head injury

INVESTIGATOR: Catharine Pedroza

Please tick box as necessary

	YES	NO
Have you read the information sheet?.....	<input type="checkbox"/>	<input type="checkbox"/>
Have you had the opportunity to ask questions and discuss the study?.....	<input type="checkbox"/>	<input type="checkbox"/>
Have your received satisfactory answers to your questions?.....	<input type="checkbox"/>	<input type="checkbox"/>
Have you received enough information about this study?.....	<input type="checkbox"/>	<input type="checkbox"/>
Who has explained this study to you?.....		
Do you understand that you are free to withdraw from this study:		
at any time	<input type="checkbox"/>	<input type="checkbox"/>
without having to give a reason for withdrawing	<input type="checkbox"/>	<input type="checkbox"/>
without affecting future contact with	<input type="checkbox"/>	<input type="checkbox"/>

Do you agree to take part in this study?.....☐

Are there any comments you wish to make?.....

.....

.....

Signature.....

Date.....

APPENDIX 5

I /WE DO WISH TO PARTICIPATE IN THE STUDY ON FATIGUE  
FOLLOWING HEAD INJURY.

Name (please print).....

Signature.....

Address.....  
.....  
.....

Phone number (including code) .....

## APPENDIX 6

### INFORMATION FOR RELATIVES ABOUT THE STUDY

#### **Title of the study**

Fatigue following acquired head injury

#### **About the study**

We know that tiredness and fatigue are extremely common after a head injury yet they have been given very little attention in the scientific and rehabilitation literature. The study aims to find out what makes people who have had head injury tired and fatigued, and to find out more about how this affects people's lives. The study will also consider whether tiredness is associated with other factors, for example, your relative's mood state or whether or not they are employed.

#### **What participation will involve**

If you agree to participate, I will visit you in your own home. Initially, I will spend time talking to you about the fatigue of your relative. With your permission, I would like to record this interview so that I have an accurate record of what you have told me. Following this, I will give you some questionnaires which I would like you to fill in. Finally, I will ask you what it felt like to participate in the research. There will be time to discuss any of your feelings arising from it at this point if you wish. You will also be given the phone numbers of local support services should you wish to discuss further any issues that arise. The visit will last approximately 2 hours, although I would like to spend some of this time with your relative.

#### **Your rights if you agree to participate**

*Participation in this study is voluntary.* Refusal to participate will not affect any treatment your relative may currently be receiving or may receive in the future. If you agree to participate, you are free to withdraw your involvement at any stage. You are also free not to answer individual questions if you do not wish to. If you decide to take part I will ask you to sign a consent form, and I have enclosed a copy of this form so that you can see what it involves.

#### **Confidentiality and results**

All identifying information will be treated as anonymous. If quotes are used in the report they will be short and it will not be possible to identify them. Tape recorded interviews will be erased following completion of the project. The only people to see the written versions of the interviews will be myself and Dr Oddy, and one other psychologist, for the purposes of coding the information you give us. A summary of the findings will be sent to any participant who is interested in the outcome of the study.

## APPENDIX 7

April 30 1999

Dear

Thank you very much for expressing an interest in the study on fatigue following brain injury. Unfortunately, because of the time limit on the study, it has been impossible to meet everyone who responded, and I regret that I will not get a chance to come and see you.

If this leaves you with any issues that you feel unhappy about, please feel free to leave me a message at , with **Wendy Julian**, and I will get back to you.

I would like to take this opportunity to thank you for volunteering to be involved in the study. I hope this will not deter you from becoming involved in any future studies from

Yours sincerely

Catharine Pedroza  
Psychologist in Clinical Training



**EAST SUSSEX, BRIGHTON AND HOVE**  
**Health Authority**

4 December 1998

Our ref: (E) 98/70

Ms C Pedroza

Direct line: 01273 403520

Fax: 01273 403505

Minicom: 01273 403590

Dear Ms Pedroza

**Study title:- Fatigue Following Acquired Brain Injury**

Thank you for your letter and enclosure of 1 December 1998.

I can confirm that the amended invitation to participate letter is satisfactory and I am writing to inform you that Chairman's Action has been given to approve this study.

It would be appreciated if, on its conclusion, you could supply a brief report to the Committee of your findings and conclusions.

Yours sincerely

Ethics Committee Administrator

## APPENDIX 9

1999

Dear Dr

**Re:**

I am writing to inform you that is currently participating in a research study investigating fatigue following brain injury.

This research is being supervised by Dr. Michael Oddy, Director of Services,  
Head Injury Rehabilitation Unit.

If you would like any further details about this study please do not hesitate to get in touch with me on

Yours sincerely

Catharine Pedroza  
Psychologist in Clinical Training

**INITIAL STRUCTURED QUESTIONS**

- 1. How old are you?**
- 2. How long ago was your injury?**
- 3. How long were you unconscious for?**
- 4. How long is the gap in your memory from the accident onwards?**
- 5. What is the first thing you remember?**
- 6. How long after the accident was this?**
- 7. What was the nature of the injury?**
- 8. What difficulties do you still experience as a result of the injury?**

## INTERVIEW SCHEDULE FOR CLIENT

*(Italics show prompts to guide thinking/line of enquiry during interview if respondent is struggling)*

**1 How would you describe tiredness or fatigue?**

*(Unpleasant, pleasant, welcome, unwelcome, affecting physical or mental functioning, sudden or slow, always present or not. Is it something that the individual thinks much about? Do they notice it in others? Do they feel that the fatigue they experience is different in some way to the way they experienced it prior to their injury?)*

**2 How do you feel when you are tired?**

*(What is the feeling like? Does it creep up? Does it suddenly appear? Is it there all the time? Is it a general feeling which prevents them completing tasks, being motivated to start tasks, wanting to start tasks but then deciding against it because of lack of energy? Is it physical, mental, both? Is it a feeling that they are resigned to in life, or is it something that they try to fight or are angry or resentful about?)*

**3 How do you know when you are tired or fatigued?**

*(What situation, place, behaviour, feelings does the person link their fatigue with? Are they describing the same signs/situations as they would have done before their head injury?)*

**4 Can you tell me about how well you sleep?**

*(Do they feel that their sleep affects their mood state and how fatigued they feel? Do they feel angry/frustrated/powerless/unconcerned about sleeping too much or not being able to sleep well? What time do you normally go to bed? What time do you normally go to sleep? Do you wake in the night? Do you know what time it is? How long are you awake before you get back to sleep? Can you get back to sleep? Do you ever sleep during the day?)*

**5 Are you on any medication?**

*(Does the person feel that their medication is to blame for feelings of fatigue? How do they feel about the medication they are on? Does it have side effects? Are they grateful for it? Do they hope to come off it in the future? What is the medicine? Has it changed recently?)*



**6**     **Are there specific times when you feel tired or fatigued? Can you tell me about them?**

*(If the person feels tired all the time, what is their mood like? Is there any time when they feel slightly less tired and are there any particular things happening at this time? Has the person given up on trying not to feel tired? Are there regular times of day when you feel tired? Do you feel tired after particular forms of activity?)*

**7**     **Are there particular situations when you feel tired or fatigued? Can you tell me about them?**

*(Is it just when the person is trying to have a good time or do something that they wish to do – such as work – i.e., is it something which has implications for their feelings of self efficacy? Is it something that they are aware of all the time? Has it prevented them from trying to do things? Does it make them worry about trying to achieve new goals? Does low mood, or fatigue, make them avoid situations (or not)? What type of situation is the person describing – anxiety provoking, threatening, unattainable, unwanted, situations related specifically to the head injury?)*

**8**     **What do you think the causes of your tiredness or fatigue are?**

*(Does the person feel that it all stems from their head injury, or do they feel low in mood, not bothered/apathetic with regard to working out the cause of their tiredness? Do they feel that it is something which will lessen with time - are they hopeful about the future? - or something which will continue in the same way?)*

**9**     **Do you think that the amount of tiredness or fatigue you experience has increased, stayed the same, or decreased following your injury? Please could you tell me why you think this?**

*(And how has this impacted on everyday life? Does the person feel that they are as successful at what they do now? Or do they feel that their tiredness precludes them from doing many of the things that they did before? Has the individual 'given up' trying to do things as a result of their fatigue?)*

## **DEBRIEFING QUESTION**

**10**     **What are your feelings about having taken part in this research?**

*(Has it been helpful to talk about subjective experience of fatigue, has it made it into a problem that the person was unaware of before. What emotions are they experiencing at the moment as a result of the feeling?)*

## INTERVIEW SCHEDULE FOR RELATIVE

*(Italics show prompts to guide thinking/line of enquiry during interview if respondent is struggling)*

**1 How would you describe tiredness or fatigue?**

*(Unpleasant, pleasant, welcome, unwelcome, affecting physical or mental functioning, sudden or slow, always present or not. Is it something that the individual thinks much about? Do they notice it in others? Do they feel that the fatigue they experience is different in some way to the way they experienced it prior to their injury?)*

**2 Can you tell me about how your relative appears to experience tiredness or fatigue?**

*(What is the feeling like? Does it creep up? Does it suddenly appear? Is it there all the time? Is it a general feeling which prevents them completing tasks, being motivated to start tasks, wanting to start tasks but then deciding against it because of lack of energy? Is it physical, mental, both? Is it a feeling that they are resigned to in life, or is it something that they try to fight or are angry or resentful about?)*

**3 How do you know when your relative is tired or fatigued?**

*(What situation, place, behaviour, feelings does the person link their fatigue with? Are they describing the same signs/situations as they would have done before their head injury?)*

**4 Can you tell me how well your relative sleeps?**

*(Do they feel that their sleep affects their mood state and how fatigued they feel? Do they feel angry/frustrated/powerless/unconcerned about sleeping too much or not being able to sleep well? What time do you normally go to bed? What time do you normally go to sleep? Do you wake in the night? Do you know what time it is? How long are you awake before you get back to sleep? Can you get back to sleep? Do you ever sleep during the day?)*

**5 Is your relative on any medication?**

*(Does the person feel that their medication is to blame for feelings of fatigue? How do they feel about the medication they are on? Does it have side effects? Are they grateful for it? Do they hope to come off it in the future? What is the medicine? Has it changed recently?)*

**6** Are there specific times when your relative feels tired or fatigued? Can you tell me about them?

*(If the person feels tired all the time, what is their mood like? Is there any time when they feel slightly less tired and are there any particular things happening at this time? Has the person given up on trying not to feel tired? Are there regular times of day when you feel tired? Do you feel tired after particular forms of activity?)*

**7** Are there particular situations when your relative feels tired or fatigued? Can you tell me about them?

*(Is it just when the person is trying to have a good time or do something that they wish to do – such as work – i.e., is it something which has implications for their feelings of self efficacy? Is it something that they are aware of all the time? Has it prevented them from trying to do things? Does it make them worry about trying to achieve new goals? Does low mood, or fatigue, make them avoid situations (or not)? What type of situation is the person describing – anxiety provoking, threatening, unattainable, unwanted, situations related specifically to the head injury?)*

**8** What do you think the causes of your relative's tiredness or fatigue are?

*(Does the person feel that it all stems from their head injury, or do they feel low in mood, not bothered/apathetic with regard to working out the cause of their tiredness? Do they feel that it is something which will lessen with time - are they hopeful about the future? - or something which will continue in the same way?)*

**9** Do you think that the amount of tiredness or fatigue your relative experiences has increased, stayed the same, or decreased following their injury? Please could you tell me why you think this?

*(And how has this impacted on everyday life? Does the person feel that they are as successful at what they do now? Or do they feel that their tiredness precludes them from doing many of the things that they did before? Has the individual 'given up' trying to do things as a result of their fatigue?)*

## **DEBRIEFING QUESTION**

**10** What are your feelings about having taken part in this research?

*(Has it been helpful to talk about subjective experience of fatigue, has it made it into a problem that the person was unaware of before. What emotions are they experiencing at the moment as a result of the feeling?)*



## APPENDIX 13

June 12 1999

Dear

You will recall that I visited you some months ago to talk about tiredness/fatigue following head injury. The following paragraphs are a very brief summary of the impression I got of your experience of tiredness/fatigue. I would be very grateful if you would read them through. I will contact you in a few days by telephone to check if you agree with the summary. When I telephone, please do not hesitate to tell me if it is an inconvenient time or if you do not wish to discuss the study further.

### *Summary of interview*

*You feel that tiredness/fatigue can be either physical, when you experience a lack of energy to move about, or mental, when it becomes more difficult to concentrate on things. You commented that people deal with tiredness/fatigue in different ways, that some people might get more irritable for example, when they are feeling tired/fatigued.*

*Personally, you feel that the tiredness/fatigue that you experience has improved a lot since you first had your injury, although you are uncertain how much it will continue to improve. You find that apart from the physical injuries you sustained you also experience some difficulties with concentration and memory. You feel that it takes you longer to do certain things and that you possibly feel more tired when you have completed them, than you would have done prior to the injury.*

*You don't associate any particular situations with tiredness/fatigue, although mid afternoon is the time when you are most likely to become aware of it. In particular, you feel that sitting around and being inactive brings on feelings of tiredness/fatigue, whereas if you are physically active you are less likely to notice it.*

Many thanks for your involvement in the project. I look forward to speaking to you on the telephone in a few days time.

Yours sincerely

Catharine Pedroza  
Psychologist in Clinical Training



memory decreased  
brain gets tired  
worries about doing something  
less alert  
difficult to get up  
withdraw  
having less control  
laziness

poor memory  
lack of clarity/focus  
lack of confidence  
mental shutdown  
stay in bed

slumping  
turn pale

**Sleep well**  
Yes  
No  
(one not sleeping well but tiredness not a problem)

good  
poor

variable (eg not as good as before)  
can be unrefreshing

**Hours of sleep**  
8 9+  
increased hours  
  
sleep as escape

7 – 8, 8-9  
9-10 more than 10 Daytime sleep  
less than 7  
tiredness can be used to avoid things

**Medication**  
antidepressant  
  
anticonvulsant

antidepressants  
anxiolytic  
anticonvulsant

**Prevents?**  
Work  
Full time  
Social things

not being able to work  
  
not coping with social situations  
interference with leisure (having to ration daily activities)

**Fatigue different?**  
Reserves low  
Inappropriate times  
Sleep does not refresh  
Now mental before only physical  
Recovery period longer  
Variable

limited energy store  
fatigue without apparent reason  
sleep not always refreshing

more effort needed for same task

**Result of injury?**  
Yes  
Because of pain  
Because of worrying – due to head injury  
Lack of stimulation  
Lack of structure

head injury led to fatigue  
pain/recovery  
anxiety  
unstimulating situations

**Prognosis**  
Improved but levelled off  
Still improving  
Think it will but it doesn't  
Has got worse

improvement  
  
not improved  
worse

**Strategies**

Rest every day  
Rationing energy  
Keep active, don't think about it

taking a break from work  
pacing yourself through the day  
doing something active, think about something else

building stamina up  
listening to music

**What it feels like**

Not being able to be bothered  
Loss of desire/will  
Too much effort required.

lack of motivation

frustrating

APPENDIX 15

Sample inter-rater reliability task

Theme

Strategies of people with brain injury in helping to combat fatigue

Categories

- A Rest every day
- B Ration energy
- C Keep active, don't think about it
- D Build stamina up
- E Push oneself

Quotes

1. 'I wear a timer that goes off every hour and when it goes off I stop what I'm doing and I sit down for at least half an hour.'
2. 'Often if I try and do something complicated in the afternoon I don't do it the best way I could, so I try and do it the next morning, try and work around it.'
3. 'Like if I start to feel tired I straight away think of other things to take my mind off it, and when I start taking my mind off it... So I try and forget about tiredness and get on and do it.'
4. 'If I do feel weary, if I get up and start doing something physical it does wake me up slightly.'
5. 'I suppose it's the fact that I don't want to get tired, so if I think about something else I won't feel tired.'
6. 'I had this aerobics tape and gradually built up what I was doing until after about four months I could do the whole tape. At the end I would feel as though I'd done it, but I didn't feel that whacked.'
7. 'Energy is kind of like money I wouldn't spend it all at once first thing in the morning, because I want to last all day..'
8. 'I normally have to come how and have a couple of hours kip before I can do anything else - like homework or go out or something.'
9. 'At work I force myself to work even if I feel really tired.'
10. 'I try and think about something else and keep swivelling my head to notice other things that are going on around me.'

APPENDIX 16

Coding example (from inter-rater reliability task)

Theme - Strategies of people with brain injury in helping to combat fatigue

Category A      Rest every day

*'I wear a timer that goes off every hour and when it goes off I stop what I'm doing and I sit down for at least half an hour.'*

*'I normally have to come home and have a couple of hours kip before I can do anything else - like homework or go out or something.'*

Category B      Ration energy

*'Often if I try and do something complicated in the afternoon I don't do it the best way I could, so I try and do it the next morning, try and work around it.'*

*'Energy is kind of like money I wouldn't spend it all at once first thing in the morning, because I want to last all day..'*

Category C      Keep active, don't think about it

*'Like if I start to feel tired I straight away think of other things to take my mind off it, and when I start taking my mind off it... So I try and forget about tiredness and get on and do it.'*

*'If I do feel weary, if I get up and start doing something physical it does wake me up slightly.'*

*'I suppose it's the fact that I don't want to get tired, so if I think about something else I won't feel tired.'*

*'I try and think about something else and keep swivelling my head to notice other things that are going on around me.'*

Category D      Build stamina up

*'I had this aerobics tape and gradually built up what I was doing until after about four months I could do the whole tape. At the end I would feel as though I'd done it, but I didn't feel that whacked.'*

Category E      Push oneself

*'At work I force myself to work even if I feel really tired.'*



# APPENDIX 17

60, 92, 98, 63, 29  
87, 72, 16, 71, 65  
18, 89, 24, 54, 28  
35, 47, 89, 27, 59  
95, 98, 52, 95, 35

23, 86, 33, 28, 44  
46, 68, 59, 67, 70  
23, 91, 89, 40, 84  
95, 57, 89, 52, 35  
16, 59, 80, 54, 48

88, 42, 34, 90, 84  
33, 43, 17, 89, 36  
87, 15, 58, 45, 52  
27, 72, 68, 95, 53  
86, 23, 60, 37, 55

27, 40, 17, 43, 25  
73, 99, 89, 29, 48  
33, 87, 58, 67, 56  
86, 84, 58, 55, 87  
84, 95, 97, 18, 47

90, 36, 92, 87, 88  
56, 73, 35, 50, 58  
46, 98, 43, 44, 89  
54, 48, 27, 46, 29  
93, 39, 40, 18, 59

27, 94, 23, 50, 85  
10, 43, 90, 74, 45  
13, 96, 55, 76, 32  
3, 94, 99, 39, 67  
3, 59, 32, 48, 96

8, 70, 93, 84, 96  
3, 27, 98, 57, 54  
1, 99, 45, 15, 67  
1, 77, 60, 51, 72  
1, 85, 37, 88, 61

16, 57, 81, 71, 17  
46, 53, 29, 73, 42  
73, 77, 63, 62, 58  
60, 59, 71, 11, 41  
82, 39, 79, 37, 45

98, 54, 52, 89, 26  
34, 40, 13, 60, 38  
86, 98, 63, 89, 52  
77, 23, 61, 63, 90  
80, 38, 42, 71, 85

70, 81, 50, 35, 54  
51, 96, 92, 75, 58  
29, 24, 25, 19, 89  
97, 91, 29, 16, 34  
49, 22, 52, 96, 89

34, 17, 11, 91, 24  
35, 88, 23, 83, 59  
72, 61, 80, 54, 70  
99, 24, 64, 11, 38  
83, 27, 65, 23, 40

37, 84, 58, 78, 53  
71, 11, 41, 82, 79  
37, 45, 98, 54, 52  
98, 36, 34, 40, 13  
60, 38, 86, 61, 66

97, 35, 89, 37, 94  
78, 28, 42, 97, 20  
42, 74, 86, 68, 40  
48, 33, 43, 28, 14  
57, 34, 68, 77, 93

27, 39, 64, 37, 14  
37, 57, 25, 68, 58  
65, 15, 72, 35, 39  
33, 50, 36, 83, 90  
84, 65, 34, 64, 96

39, 32, 85, 48, 53  
83, 36, 10, 76, 39  
54, 66, 98, 33, 64  
68, 67, 94, 95, 58  
42, 39, 35, 57, 77

63, 63, 99, 79, 73  
23, 88, 24, 88, 46  
42, 73, 42, 71, 24  
23, 98, 27, 23, 26  
34, 78, 59, 57, 58

58, 88, 48, 98, 17  
64, 56, 89, 39, 35  
36, 64, 87, 86, 65  
84, 74, 33, 31, 88  
79, 27, 24, 55, 72

49, 46, 67, 69, 97  
94, 46, 86, 65, 56  
57, 37, 29, 29, 34  
68, 76, 25, 22, 55  
75, 97, 57, 75, 56

48, 35, 26, 54, 49  
57, 24, 45, 61, 91  
96, 49, 38, 55, 63  
85, 26, 25, 79, 24  
38, 41, 37, 32, 86

42, 48, 37, 97, 24  
87, 69, 24, 37, 75  
97, 49, 95, 24, 14  
67, 80, 73, 91, 74  
58, 56, 66, 16, 87

70, 58, 54, 31, 94  
38, 92, 52, 43, 94  
39, 75, 78, 68, 66  
86, 80, 94, 39, 89  
19, 66, 44, 63, 77

APPENDIX 18

Please place a mark on each line to indicate how much tiredness/fatigue is a problem to you.

Tiredness/fatigue  
has a major impact  
on my life

Tiredness/fatigue  
is not a problem  
at all for me

-----I-----

I rarely feel  
tired/fatigued

I almost  
always feel  
tired/fatigued

-----I-----

14. Resting lessens my fatigue.	1	2	3	4	5	6	7
15. Sleeping lessens my fatigue.	1	2	3	4	5	6	7
16. Cool temperatures lessen my fatigue.	1	2	3	4	5	6	7
17. Positive experiences lessen my fatigue.	1	2	3	4	5	6	7
18. I am easily fatigued.	1	2	3	4	5	6	7
19. Fatigue interferes with my physical functioning.	1	2	3	4	5	6	7
20. Fatigue causes frequent problems for me.	1	2	3	4	5	6	7
21. My fatigue prevents sustained physical functioning.	1	2	3	4	5	6	7
22. Fatigue interferes with carrying out certain duties and responsibilities.	1	2	3	4	5	6	7
23. Fatigue predated other symptoms of my injury.	1	2	3	4	5	6	7
24. Fatigue is my most disabling symptom.	1	2	3	4	5	6	7
25. Fatigue is among my three worst disabling symptoms.	1	2	3	4	5	6	7
26. Fatigue interferes with my work, family or social life.	1	2	3	4	5	6	7
27. Fatigue makes other symptoms worse.	1	2	3	4	5	6	7
28. Fatigue I now experience is different in quality or severity than the fatigue I experienced before my injury.	1	2	3	4	5	6	7
29. I experience prolonged fatigue after exercise.	1	2	3	4	5	6	7

# APPENDIX 21

P C L

1 = almost never      2 = sometimes      3 = often      4 = almost all

1	I have trouble sleeping	1....	2....	3....	4..
2	I have rapid mood changes	1....	2....	3....	4..
3	I have difficulty becoming interested in things	1....	2....	3....	4..
4	I use a wheelchair	1....	2....	3....	4..
5	I do the same thing over & over again	1....	2....	3....	4..
6	I am generous towards others	1....	2....	3....	4..
7	I am restless	1....	2....	3....	4..
8	I have difficulty with hearing	1....	2....	3....	4..
9	I get ideas stuck in my head	1....	2....	3....	4..
10	I am unreasonable	1....	2....	3....	4..
11	I repeat words & phrases	1....	2....	3....	4..
12	I cry easily	1....	2....	3....	4..
13	I lose balance	1....	2....	3....	4..
14	I am sexually disinhibited	1....	2....	3....	4..
15	I am confident	1....	2....	3....	4..
16	I am upset by changes in routine	1....	2....	3....	4..
17	I think only of myself	1....	2....	3....	4..
18	I feel anxious or worried	1....	2....	3....	4..
19	I behave childshly	1....	2....	3....	4..
20	I have fits (seizures)	1....	2....	3....	4..
	I am affectionate towards others	1....	2....	3....	4..
	I am easily tired	1....	2....	3....	4..
	I have few leisure interests	1....	2....	3....	4..
	I am quick to lose my temper	1....	2....	3....	4..
	I have difficulty engaging in sex	1....	2....	3....	4..
	I have difficulty with seeing	1....	2....	3....	4..



	1 = almost never	2 = sometimes	3 = often	4 = almost always
7 I am verbally aggressive	1....	2....	3....	4....
8 I am physically aggressive	1....	2....	3....	4....
9 I have memory difficulties	1....	2....	3....	4....
0 I am withdrawn	1....	2....	3....	4....
1 I am incontinent	1....	2....	3....	4....
2 I get very sad, fed up	1....	2....	3....	4....
3 I am intolerant of others	1....	2....	3....	4....
4 I just sit	1....	2....	3....	4....
5 I feel people don't care about me	1....	2....	3....	4....
6 I walk unaided	1....	2....	3....	4....
7 I don't pick up social cues	1....	2....	3....	4....
8 I am suspicious/mistrustful of others	1....	2....	3....	4....
9 I feel depressed	1....	2....	3....	4....
0 I attend to personal hygiene	1....	2....	3....	4....
1 I am impulsive, act without thought	1....	2....	3....	4....
2 I want sex less often than before	1....	2....	3....	4....
3 I am irritable	1....	2....	3....	4....
4 My behaviour is socially inappropriate	1....	2....	3....	4....
5 I am lacking in initiative	1....	2....	3....	4....
6 I have difficulty organising activities	1....	2....	3....	4....
7 I get stuck in the middle of doing things	1....	2....	3....	4....
8 I talk of suicide	1....	2....	3....	4....
9 I seem to have no control over emotions	1....	2....	3....	4....
0 I am kind	1....	2....	3....	4....

1 = almost never    2 = sometimes    3 = often    4 = almost always

1	I feel unwell	1....	2....	3....	4....
2	I need a lot of attention	1....	2....	3....	4....
3	I am clumsy, bump into things or drop things	1....	2....	3....	4....
4	I am disoriented or lost	1....	2....	3....	4....
5	I have difficulty with sense of taste or smell	1....	2....	3....	4....
6	I am confused about things	1....	2....	3....	4....
7	I am insensitive to others	1....	2....	3....	4....
8	My feelings get hurt easily	1....	2....	3....	4....
9	I need to keep things tidy	1....	2....	3....	4....
10	I behave in odd ways	1....	2....	3....	4....
11	I <u>express</u> odd <u>ideas</u>	1....	2....	3....	4....
12	I feel unwanted	1....	2....	3....	4....
13	I have headaches	1....	2....	3....	4....
14	I laugh for no obvious reason	1....	2....	3....	4....
15	I have difficulty speaking	1....	2....	3....	4....
16	I have difficulty expressing thoughts	1....	2....	3....	4....
17	I have to be told what to do	1....	2....	3....	4....
18	I talk too much	1....	2....	3....	4....
19	I am dependable	1....	2....	3....	4....
20	I complain about people and things in general	1....	2....	3....	4....
21	I refuse to compromise	1....	2....	3....	4....
22	I have dizzy spells	1....	2....	3....	4....
23	I talk about being angry with certain people	1....	2....	3....	4....
24	I am responsible	1....	2....	3....	4....
25	I have difficulty concentrating	1....	2....	3....	4....
26	Other:.....	1....	2....	3....	4....

	<u>1 = almost never</u>	<u>2 = sometimes</u>	<u>3 = often</u>	<u>4 = almost always</u>
27	Is verbally aggressive	1....	2....	3.... 4....
28	Is physically aggressive	1....	2....	3.... 4....
29	Has memory difficulties	1....	2....	3.... 4....
30	Is withdrawn	1....	2....	3.... 4....
31	Is incontinent	1....	2....	3.... 4....
32	Gets very sad, fed up	1....	2....	3.... 4....
33	Is intolerant of others	1....	2....	3.... 4....
34	Just sits	1....	2....	3.... 4....
35	Feels people don't care about him/her	1....	2....	3.... 4....
36	Walks unaided	1....	2....	3.... 4....
37	Doesn't pick up social cues	1....	2....	3.... 4....
38	Is suspicious/mistrustful of others	1....	2....	3.... 4....
39	Feels depressed	1....	2....	3.... 4....
40	Attends to personal hygiene	1....	2....	3.... 4....
41	Is impulsive, acts without thought	1....	2....	3.... 4....
42	Wants sex less often than before	1....	2....	3.... 4....
43	Is irritable	1....	2....	3.... 4....
44	Behaviour is socially inappropriate	1....	2....	3.... 4....
45	Is lacking in initiative	1....	2....	3.... 4....
46	Has difficulty organising activities	1....	2....	3.... 4....
47	Gets stuck in middle of doing things	1....	2....	3.... 4....
48	Talks of suicide	1....	2....	3.... 4....
49	Seems to have no control over emotions	1....	2....	3.... 4....
50	Is kind	1....	2....	3.... 4....
51	Feels unwell	1....	2....	3.... 4....
52	Needs a lot of attention	1....	2....	3.... 4....

1 = almost never      2 = sometimes      3 = often      4 = almost always

53	Clumsy, bumping into things or dropping things	1....	2....	3....	4....
54	Seems disoriented or lost	1....	2....	3....	4....
55	Has difficulty with sense of taste or smell	1....	2....	3....	4....
56	Seems confused about things	1....	2....	3....	4....
57	Is insensitive to others	1....	2....	3....	4....
58	Feelings get hurt easily	1....	2....	3....	4....
59	Needs to keep things tidy	1....	2....	3....	4....
60	Behaves in odd ways	1....	2....	3....	4....
61	Expresses odd ideas	1....	2....	3....	4....
62	Feels unwanted	1....	2....	3....	4....
63	Has headaches	1....	2....	3....	4....
64	Laughs for no obvious reason	1....	2....	3....	4....
65	Has difficulty speaking	1....	2....	3....	4....
66	Has difficulty expressing thoughts	1....	2....	3....	4....
67	Has to be told what to do	1....	2....	3....	4....
68	Talks too much	1....	2....	3....	4....
69	Is dependable	1....	2....	3....	4....
70	Complains about people and things in general	1....	2....	3....	4....
71	Refuses to compromise	1....	2....	3....	4....
72	Has dizzy spells	1....	2....	3....	4....
73	Talks about being angry with certain people	1....	2....	3....	4....
74	Is responsible	1....	2....	3....	4....
75	Has difficulty concentrating	1....	2....	3....	4....
76	Other:.....	1....	2....	3....	4....